

Care of the Complex Chronically Ill Child by Generalist Pediatricians: Lessons Learned from Pediatric Palliative Care

Date:

Apr 2013

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BACKGROUND AND OBJECTIVE: Parents of children with complex chronic conditions report fragmented care, unmet medical needs, and financial strain from health care costs. The aim of this study was to identify both prevalent themes discussed during pediatric palliative care consultation of patients with complex chronic conditions cared for by pediatric generalists and variation in consultation content by age and timing of consultation in disease course.

METHODS: Forty randomly selected initial inpatient or outpatient consultation notes authored by the pediatric palliative care team at an academic, tertiary care children's hospital. Inclusion required that patients were primarily cared for by general pediatricians, pediatric hospitalists, or pediatric intensivists, instead of subspecialists. Qualitative analysis by 5 team members utilizing consensus-based findings was used to develop themes. Descriptive statistics were used to describe variations in themes across age and disease course.

RESULTS: Common themes included thorough review of patient baseline functioning, current symptoms, assessment of family's understanding of the prognosis of the patient, coordination of communication with other medical teams and outpatient health care services, consideration of caregiver resources and burdens, and offering a framework for decision-making. Variation in consult themes by age/disease course included more discussion of communication problems and symptom management when patients were at their baseline, but otherwise little variation was found.

CONCLUSIONS: Common themes covered in initial consultations correspond with documented unmet needs for chronically ill children. There was no significant variation in consultation themes by age/disease course, suggesting that generalists could broadly apply palliative care techniques to improve family-centered care.

Journal:

[Hospital Pediatrics](#)

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