

- Berry JG, Hall M, Hall DE, et al. Inpatient growth and resource use in 28 children's hospitals: a longitudinal, multi-institutional study. *JAMA Pediatr.* 2013;167(2):170–177.
- Bettle AM, Latimer MA. Maternal coping and adaptation: a case study examination of chronic sorrow in caring for an adolescent with a progressive neurodegenerative disease. *Can J Neurosci Nurs.* 2009;31(4):15–21.
- Blume ED, Balkin EM, Aiyagari R, et al. Parental perspectives on suffering and quality of life at end-of-life in children with advanced heart disease: an exploratory study. *Pediatr Crit Care Med.* 2014;15(4):336–342.
- Burke RT, Alverson B. Impact of children with medically complex conditions. *Pediatrics.* 2010;126(4):789–790.
- Burns KH, Casey PH, Lyle RE, et al. Increasing prevalence of medically complex children in US hospitals. *Pediatrics.* 2010;126(4):638–646.
- Carnevale FA, Alexander E, Davis M, et al. Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. *Pediatrics.* 2006;117(1):e48–e60.
- Carnevale FA, Rehm RS, Kirk S, et al. What we know (and don't know) about raising children with complex continuing care needs. *J Child Health Care.* 2008;12(1):4–6.
- Clements PT, Vigil GJ, Manno MS, et al. Cultural perspectives of death, grief, and bereavement. *J Psychosoc Nurs Ment Health Serv.* 2003;41(7):18–26.
- Coffey JS. Parenting a child with chronic illness: a metasyntesis. *Pediatr Nurs.* 2006;32(1):51–59.
- Cohen E, Friedman J, Nicholas DB, et al. A home for medically complex children: the role of hospital programs. *J Healthc Qual.* 2008;30(3):7–15.
- Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics.* 2011;127(3):529–538.
- Coker TR, Rodriguez MA, Flores G. Family-centered care for US children with special health care needs: who gets it and why? *Pediatrics.* 2010;125(6):1159–1167.
- Corlett J, Twycross A. Negotiation of parental roles within