Parental stress and quality of life in children with neuromuscular disease.

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Abstract
This study examined health-related quality of life and parental stress among pediatric neuromuscular patients with or without home mechanical ventilation. Parents completed the Parenting Stress Index or Stress Index for Parents of Adolescents, depending on their child's age. The Pediatric Quality of Life Inventory measured quality of life in children with neuromuscular disease. One hundred and nine families participated; 19 (17%) families had a child with neuromuscular disease requiring home mechanical ventilation. Overall, children on home mechanical ventilation had significantly lower mean total Pediatric Quality of Life Inventory scores than nonventilated children (47.9 versus 61.5, respectively; P = 0.013). No significant difference in mean total stress scores was found between parents of pediatric neuromuscular patients with or without home mechanical ventilation. Despite their child's lower health-related quality of life, parents of pediatric neuromuscular patients requiring home mechanical ventilation did not report significantly higher parental stress than parents of nonventilated children or parents in the normative sample. We postulated that for parents living with the constant demands of caring for their child with neuromuscular disease requiring home mechanical ventilation, these caretaking demands, over time, had become part of "normal" life and were not identified as creating additional stress.


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