

# Differing Perceptions Regarding Quality of Life and Inpatient Treatment Goals for Children With Severe Disabilities



Robyn Nolan, MD; Brenda Luther, PhD, RN; Paul Young, MD; Nancy A. Murphy, MD

From the Department of Developmental Behavioral Pediatrics, University of Colorado, Denver, Aurora, Colo (Dr Nolan); College of Health Professions, Western Governors University, Salt Lake City, Utah (Dr Luther); and Department of Pediatrics, University of Utah School of Medicine, Salt Lake City, Utah (Drs Young and Murphy)

The authors declare that they have no conflict of interest.

Address correspondence to Robyn Nolan, MD, Department of Developmental Behavioral Pediatrics, University of Colorado, Denver, 13123 E 16th Avenue, Box 140, Aurora, CO 80045 (e-mail: [robyn.nolan@ucdenver.edu](mailto:robyn.nolan@ucdenver.edu)).

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## ABSTRACT

**OBJECTIVE:** To describe and compare during an acute hospitalization the perceptions of parents, pediatric interns, and pediatric hospitalists regarding the long-term health-related quality of life (HRQoL) of children with severe disabilities when not hospitalized and to identify treatment goals.

**METHODS:** Parents of children with severe disabilities aged 5 to 18 years, as well as the intern and hospitalist caring for the child during acute hospitalizations at a tertiary care center in Salt Lake City, Utah, participated in this study. All participants completed the KIDSCREEN-10 and an investigator-developed survey; a subset was interviewed to qualitatively ascertain perceptions of the child's HRQoL before the current acute illness. Responses were summarized with descriptive statistics and content analysis.

**RESULTS:** We enrolled 115 subjects. Overall, parents rated the HRQoL of their children significantly higher than did either group of physicians on both the KIDSCREEN-10 ( $37.4 \pm 3.9$  vs  $29.6 \pm 5.5$ ,  $P < .001$ ) and the investigator-developed survey ( $30.3 \pm 5.9$  vs  $26.3 \pm 5.5$ ,  $P < .001$ ). Parents described the

HRQoL of their children more positively and broadly than did physicians. Parents and physicians also expressed different goals for treatment. Parents expressed optimism despite uncertainty regarding their child's future, whereas physicians anticipated increased medical complications and focused on caregiver burden.

**CONCLUSIONS:** Parents of children with severe disabilities rated their children's long-term HRQoL higher than physicians did. Such discrepancies may increase tensions and hinder shared decision-making efforts during acute hospitalizations. Explicit discussions between parents and physicians regarding the HRQoL of children with severe disabilities and treatment goals may facilitate care processes for everyone involved.

**KEYWORDS:** caregivers; child; lifestyle; parents; pediatric; persons with disabilities; physically disabled; physicians; quality of life

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## WHAT'S NEW

Parents believe that their children with severe disabilities have a higher health-related quality of life than physicians do. Parents and physicians often differ regarding treatment goals and outcome expectations during an acute hospitalization of a child with a severe disability. Awareness of these differences may help facilitate communication and strengthen parent–physician partnerships.

OVER THE PAST 50 years, the number of children with disabilities has tripled.<sup>1</sup> Approximately 1 in 6 US children has a developmental disability,<sup>2</sup> and nearly a half a million children are unable to care for themselves.<sup>3</sup> Technological advances have allowed children with severe disabilities to survive and thrive longer than ever before. This has led to increased needs for medical care, reliance on technologies and polypharmacy, and frequent, prolonged hospitalizations.<sup>4</sup> Recurrent hospitalizations for children with chronic

conditions are common and may relate to gaps in care coordination, ambulatory health care, and family–provider partnerships regarding treatment goals.<sup>5,6</sup>

Quality of life (QoL) assessments can guide treatment plans. Yet very young children or those with severe disabilities are unable to self-report their QoL, so we must rely on proxies. Most commonly, parents or physicians act as proxies, although evidence suggests that they both tend to underrate QoL compared with patients themselves.<sup>7–9</sup> Parents and physicians also differ in their perceptions of health-related QoL (HRQoL) of children with chronic illnesses,<sup>8,10</sup> particularly when children have severe cerebral palsy (CP) or chronic neurological conditions.<sup>11</sup> Similarly, parents of children with CP and intellectual disabilities rate the HRQoL of their children higher than do professional caregivers (teachers, therapists, aides).<sup>12</sup> Parents of children with disabilities are more than twice as likely than other parents to report inadequate time, listening, information sharing, and partnerships with their pediatricians.<sup>13</sup> Discordant perceptions between parents

and providers regarding a child's QoL may further contribute to parent-provider tensions when establishing shared treatment goals.

Acute illnesses in children with severe disabilities account for a significant proportion of admissions to pediatric hospitals, and life changing decisions are often made during acute hospitalizations. Ideally, parents and health care providers collaborate in the development of treatment plans, including decisions regarding surgeries or comfort care. Although treatment goals are likely influenced by perceptions of a child's QoL, how parents and pediatricians perceive the HRQoL of children with severe disabilities during hospitalizations for acute illnesses has not been studied.

Hospitalist medicine is the fastest growing specialty in the United States,<sup>14</sup> and hospitalists play a key role in shared decision making with families.<sup>15</sup> In academic hospitals, residents are often the primary contact for families and intimately involved in decision making. When there is no clear best option, decisions may be preference sensitive and influenced by personal and societal perceptions of childhood disability. Differing perceptions may lead to tensions within care teams, and treatment options may not align with parents' goals. The objectives of this study were to describe and compare during an acute hospitalization the perceptions of parents, pediatric interns, and pediatric hospitalists regarding overall long-term HRQoL of children with severe disabilities when they are not hospitalized, and to identify treatment goals and expected outcomes. Our goals were to provide insights from this combined quantitative and qualitative study that might guide physicians as they care for increasing populations of children with severe disabilities and their families.

## SUBJECTS AND METHODS

### SETTING

This study was conducted at Primary Children's Hospital (PCH) in Salt Lake City, Utah. PCH, with 252 beds, is the only pediatric tertiary care center in the Intermountain West (the states of Utah, Nevada, Montana, Wyoming, and Idaho). PCH provides most of the specialty care for children with disabilities and chronic, complex conditions in the region. Children with medically complex conditions account for 23% of admissions to pediatric hospitalist teams. PCH is the primary teaching site for the residency programs of the University of Utah's Department of Pediatrics. Of the 80 pediatric residents, 24 are interns. The hospitalist group consists of 26 physicians.

### DESIGN

We used both quantitative and qualitative methods to ascertain the perceptions of parents, pediatric interns, and hospitalists of the HRQoL of children with severe disabilities.

### SUBJECTS

The principal investigator (PI) and senior pediatric residents leading resident teams identified children between 5 and 18 years with severe disabilities through daily

screenings of the inpatient team census. Children younger than 5 years old were excluded because typically developing children approach functional independence and school readiness by 5 years of age, whereas those with severe disabilities remain functionally dependent, thus emphasizing differences in parenting requirements.<sup>16</sup> Only children admitted by pediatric resident teams with hospitalist attendings were eligible for this study. We defined children with severe disabilities as those who continuously required a great deal of help or total assistance in 3 out of the following 4 functional domains: social participation, communication, self-care, and mobility.<sup>17</sup> For each child, we identified triads consisting of the parent, the pediatric intern, and the attending hospitalist. If a parent declined participation, then the triad was not enrolled. If one of the physicians declined participation, data from the parent and other physician were still included. For the purposes of the study, we use the term *parent* to refer to the primary caregiver who rendered daily care for the child continuously for at least 6 months before enrollment. All participants provided written informed consent. The study was approved by the institutional review board (IRB) of the University of Utah and was exempted by the IRB of Intermountain Healthcare.

### QUANTITATIVE DATA

We quantified the perceptions of parents, interns, and hospitalists regarding the long-term HRQoL of children with severe disabilities using 2 measures: the KIDSCREEN-10 index and an investigator-developed supplemental survey. The KIDSCREEN-10 is a reliable (Cronbach's alpha = 0.82) generic HRQoL instrument for children 8 to 18 years of age that has been validated on children and parents in several European countries.<sup>18</sup> This measure has also been used previously for health care providers.<sup>12</sup> The KIDSCREEN-10 measures key aspects of HRQoL (physical well-being, psychological well-being, social support and peers, financial resources) using a 5-point Likert scale (1 = not at all, 5 = extremely) to yield a global summary score (maximum possible score of 50).<sup>18</sup> Although it is a general instrument, the KIDSCREEN-10 performs well for children with disabilities such as CP and is less likely than other HRQoL measures to be limited by floor and ceiling effects.<sup>19</sup> Physicians were instructed to regard the person referred to in the KIDSCREEN-10 as their patient rather than their child. Participants were asked to consider the child in their baseline state (how they had been before their current illness) instead of the printed direction of "thinking about the last week." In addition, the investigators developed a 9-item supplemental survey ([Online Appendix](#)) to further assess long-term HRQoL, also using a 5-point Likert scale (1 = never, 5 = always; maximum possible score of 45). The supplemental survey was designed to assess concerns specific to children with severe disabilities not addressed by the KIDSCREEN-10 and was piloted with 3 sets of parents of children with severe disabilities before the investigation. During the pilot, parents were asked to provide feedback on the language and content of the questions.

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