

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



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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.

The statistical analysis compares the perceptions of the child's HRQoL by the 3 rater groups to detect differences between responses of parents and interns, parents, and hospitalists, and interns and hospitalists. Each child's HRQoL was rated 3 times, yielding ratings from each of the 3 groups, on 20 Likert scale (1 to 5) items. Comparisons were made by a paired sample Wilcoxon sign rank test for each of the 20 items. To adjust for the multiplicity of comparisons, the Benjamini-Hochberg procedure was used. This procedure maintains the false discovery rate, keeping the number of false positive conclusions to 5% within a rater pair. A difference was computed for each pair, which represents the number of categories that differed on the Likert scales. These differences are displayed using a median and interquartile range (25th and 75th percentiles) to summarize differences. *P* values of less than .05 were considered significant.

### QUALITATIVE DATA

Consecutively enrolled triads participated in individual semistructured interviews with the PI after survey completion. Participants were asked 5 questions: What are your expectations for this child's future? What role does this child play in the family? How have health care interventions affected this child? What issues most affect this child's QoL? How can you most positively influence this child's QoL? We continued the semistructured interviews until continuous comparative data analysis demonstrated saturation of themes, attained after 16 triads. The interviews were recorded and transcribed verbatim.

We coded, categorized, and linked categories of interview responses using the systematic methods of Glaser and Strauss.<sup>20</sup> Initial coding of data was accomplished by reviewing transcripts to identify and label data with substantive codes that described each triad's responses and was performed by 2 separate reviewers. Codes were compared with conceptually related codes and grouped into categories. Throughout the analysis, the properties, characteristics, and dimensions of categories were developed. Some categories were regrouped together and subsumed as 1 category after examination of similar properties. Written memos documented the PI's ideas about the emerging categories and the properties and dimensions of the categories. A research team consisting of the PI (RN), a pediatric physiatrist (NM), and a pediatric nurse/qualitative data analyst (BL) met regularly to assure accuracy and agreement of emerging themes.

## RESULTS

### QUANTITATIVE FINDINGS

We enrolled 39 triads between July 2010 and March 2011. Fifty-four percent of the children were girls. The admitting diagnoses and underlying chronic conditions of the children varied widely, although the most common underlying chronic conditions were CP and seizure disorder (Table 1). Nearly all of the primary caregivers were biologic parents; 2 were adoptive parents, and 1 was a child's grandfather. Sixty-four percent of the hospitalists were men; their mean length of time practicing as a hospitalist was 4.1

**Table 1.** Characteristics of 39 Children With Severe Disabilities

|   |      |  |  |
|---|------|--|--|
| Admitting diagnoses                     |      |  |  |
| • Pneumonia                             | (9)  |  |  |
| • Respiratory distress                  | (7)  |  |  |
| • Seizures                              | (7)  |  |  |
| • Abdominal distension/feeding/diarrhea | (7)  |  |  |
| • Fever                                 | (5)  |  |  |
| • Urosepsis                             | (3)  |  |  |
| • Melena                                | (2)  |  |  |
| • Sleep apnea                           | (2)  |  |  |
| • Postoperative care                    | (2)  |  |  |
| • Intrathecal baclofen pump malfunction | (1)  |  |  |
| • Stroke                                | (1)  |  |  |
| Chronic conditions                      |      |  |  |
| • Cerebral palsy                        | (25) |  |  |
| • Seizure disorder                      | (23) |  |  |
| • Static encephalopathy                 | (7)  |  |  |
| • Chromosomal abnormalities             | (5)  |  |  |
| • Panhypopituitarism                    | (4)  |  |  |
| • Congenital heart disease              | (2)  |  |  |
| • Leukodystrophy                        | (2)  |  |  |
| • Encephalocele                         | (1)  |  |  |
| • Lissencephaly                         | (1)  |  |  |
| • Spina bifida                          | (1)  |  |  |
| • Myotonic dystrophy                    | (1)  |  |  |
| Assistive technologies                  |      |  |  |
| • Gastrostomy tube                      | (12) |  |  |
| • Tracheostomy                          | (6)  |  |  |
| • Ventriculoperitoneal shunt            | (7)  |  |  |
| • Intrathecal baclofen pump             | (4)  |  |  |

years. Interns were predominantly women, and 5 had medical experience before medical school. Some hospitalists and interns participated more than once because they were responsible for the care of more than 1 eligible child during this study. Two hospitalists declined to participate. Characteristics of study participants are detailed in Table 2.

Comparisons of survey responses are shown in Table 3. There were no significant differences between the ratings of interns and hospitalists, although differences between the 2 groups of physicians with respect to loneliness, sadness, time to themselves, and experience of pleasure approached significance ( $P = .08$ ), with intern ratings being somewhat lower. On nearly all the individual items in both surveys, parents viewed their child's HRQoL higher than either of the physician groups. As shown in Table 4, composite scores of both the KIDSCREEN-10 and supplemental surveys were significantly higher for parents than for interns or hospitalists (KIDSCREEN-10: mean parent score = 37.4; mean physician score = 29.6;  $P < .001$ ; supplemental survey: mean parent score = 30.3; mean physician score = 26.3;  $P < .001$ ).

### QUALITATIVE FINDINGS

Themes that emerged through semistructured interviews related to future expectations (Table 5), the benefit of

**Table 2.** Characteristics of Study Participants

| Characteristic              | Parents  | Interns  | Hospitalists |
|-----------------------------|----------|----------|--------------|
| N                           | 40       | 20       | 22           |
| Age range, y                | 23–57    | 26–32    | 29–52        |
| Female sex                  | 30 (75%) | 17 (85%) | 8 (36%)      |
| No. enrolled more than once | 0        | 13 (65%) | 7 (32%)      |

**Table 3.** Comparison of Responses for KIDSCREEN 10 and Supplemental Survey\*

| Characteristic                            | Parent Minus Intern |                  | Parent Minus Hospitalist |                  | Intern Minus Hospitalist |                  |
|---|---------------------|------------------|--------------------------|------------------|--------------------------|------------------|
|   | Median (IQR)        | Adjusted P Value | Median (IQR)             | Adjusted P value | Median (IQR)             | Adjusted P value |
| <b>KIDSCREEN 10</b>                       |                     |                  |                          |                  |                          |                  |
| Physically fit/well                       | 1 (0, 2)            | .002             | 1 (0, 2)                 | .011             | 0 (−1, 1)                | .93              |
| Energy                                    | 0 (0, 1)            | .005             | 0 (0, 1)                 | .007             | 0 (0, 1)                 | .94              |
| Sad                                       | 0 (0, 1)            | .013             | 0 (0, 1)                 | .62              | 0 (−1, 0)                | .08              |
| Lonely                                    | 1 (0, 1)            | <.001            | 1 (−1, 1)                | .15              | −1 (−1, 0)               | .023             |
| Self time                                 | 1 (−1, 1)           | .17              | 0 (−1, 1)                | .88              | −1 (−1, 0)               | .08              |
| Able to do                                | 1 (0, 2)            | .001             | 1 (0, 2)                 | .003             | 0 (−1, 1)                | .94              |
| Parents treat fairly                      | 0 (0, 1)            | .012             | 0 (0, 1)                 | .19              | 0 (−1, 1)                | .96              |
| Fun with friends                          | 1 (0, 2)            | .001             | 1 (0, 2)                 | .007             | 0 (−1, 0)                | .35              |
| Well at school                            | 2 (0, 3)            | <.001            | 2 (1, 3)                 | .001             | 0 (−1, 1)                | .94              |
| Pay attention                             | 1 (0, 2)            | .002             | 1 (0, 2)                 | .003             | 0 (−1, 1)                | .99              |
| General                                   | 1 (0, 2)            | .002             | 0 (0, 1)                 | .38              | −1 (−1, 0)               | .08              |
| <b>Investigator-developed survey</b>      |                     |                  |                          |                  |                          |                  |
| How often child interacts                 | 1 (0, 2)            | .007             | 1 (0, 1)                 | .020             | 0 (−1, 1)                | .94              |
| Experience pleasure                       | 1 (0, 1)            | .002             | 0 (0, 1)                 | .30              | 0 (−1, 0)                | .07              |
| Comfortable                               | 0 (0, 1)            | .042             | 0 (0, 1)                 | .30              | 0 (0, 0)                 | .35              |
| How often happy                           | 0 (0, 1)            | .001             | 0 (0, 1)                 | .003             | 0 (−1, 0)                | .36              |
| Family                                    | 0 (0, 1)            | .12              | 1 (−1, 1)                | .19              | 0 (−1, 1)                | .93              |
| School participation                      | 1 (0, 2)            | .001             | 1 (0, 2)                 | .003             | 0 (−1, 1)                | .94              |
| Community                                 | 1 (0, 1)            | .010             | 0 (−1, 1)                | .30              | 0 (−1, 0)                | .13              |
| Medical interruptions                     | 0 (−1, 1)           | .91              | 0 (−1, 1)                | .92              | 0 (−1, 1)                | .94              |
| Medical interventions and quality of life | 0 (−1, 1)           | .28              | 0 (−1, 1)                | .86              | 0 (−1, 0)                | .13              |

IQR = interquartile range (25th, 75th percentiles).

\*P values are adjusted for 20 comparisons using the Benjamini-Hochberg procedure.

medical interventions (Table 6), and factors that influence the HRQoL of children with severe disabilities (Table 7).

**FUTURE EXPECTATIONS**

Parents expected their children to continue learning and to gain independence, but they voiced emerging doubts regarding their futures. Parents were less likely than physicians to discuss issues of morbidity and mortality. Many parents stated that they could not plan for the future because of unpredictable circumstances. By comparison, hospitalists focused on the life-limiting nature of the disabilities and the long-term dependence of the children on their families. Physicians envisioned more dependence, continued heavy caregiver burden, and further hospitalizations, and they focused on keeping the child at home and supporting the family.

**BENEFITS OF MEDICAL INTERVENTIONS**

Parents generally thought that medical interventions had benefited the function and survival of their children. Several

**Table 4.** Comparison of Health-Related Quality of Life Among Parents, PGY-1, and Hospitalists

| Measure                       | Mean (SD) for: |            |              |                |
|-------------------------------|----------------|------------|--------------|----------------|
|                               | Parents        | Intern     | Hospitalists | All Physicians |
| KIDSCREEN-10                  | 37.4 (3.9)*    | 29.2 (6.0) | 30.2 (5.0)   | 29.6 (5.5)     |
| Investigator-developed survey | 30.3 (5.9)*    | 25.7 (5.7) | 27.1 (5.4)   | 26.3 (5.5)     |

PGY = postgraduate year; SD = standard deviation.

\*P < .001 for comparison between parents, PGY-1, and hospitalists separately and combined (t test).

parents mentioned that although frequent hospitalizations interrupted routines and caused anxiety, the interventions were valued because they improved comfort. Physicians agreed that medical interventions had increased the survival of children with severe disabilities, although they were not sure that this was a positive outcome. Hospitalists worried about doing harm; they recognized that previous medical interventions had prolonged life but were concerned that this might also lead to increased suffering.

**FACTORS INFLUENCING HRQoL**

Hospitalists identified the primary disability as the main determinant of HRQoL and focused on decreasing caregiver burden for families through care coordination, avoidance of complications, and anticipatory guidance.

**Table 5.** Future Expectations

|   |
|---|
| Parent  |
| <i>Uncertain of future events</i>                                     |
| • “I am in denial about the future, when I can’t handle him anymore.” |
| • “We live day by day.”   |
| <i>Goals</i>  |
| • “Be independent, learn to communicate.”                             |
| • “Learn with help from school and us.”                               |
| • “Be as comfortable and happy as possible.”                          |
| Intern/Hospitalist  |
| <i>Expecting limited trajectory</i>                                   |
| • “She’s already at the pinnacle of her existence.”                   |
| • “Her behavior and development won’t change.”                        |
| • “Be dependant the rest of his life.”                                |
| <i>Goals</i>  |
| • “Supporting her caregivers’ wishes.”                                |
| • “Keep [the patient] out of the hospital.”                           |
| • “Coordinate his care.”  |

**Table 6.** Benefits of Medical Intervention

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Parent

*Overall beneficial*

- “Interrupted routines and caused anxiety, but made her more comfortable.”
- “It has impacted us in a positive way in that she’s still here.”

Intern

*Uncertainty as to benefit*

- “I hope that they’ve improved her quality of life and were very beneficial.”
- “I would assume that those things were beneficial.”

Hospitalist

*Have kept them alive but questioning quality of life*

- “We prolong a lot of kids’ lives, for the better or for the worse.”
- “I don’t know that we haven’t imposed more suffering than we have well-being with our multiple medical interventions.”

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Conversely, parents and interns thought that HRQoL was determined more by the child’s ability to communicate and participate. Parents thought that their caregiving roles had a large influence on their child’s HRQoL. Parents emphasized the importance of relationships on HRQoL of their children. Inclusion and emotional interactions with siblings, classmates, and caregivers were deemed at least as important as physical interactions. Although parents recognized the value of social and emotional interactions for their children, physicians recognized the commitment, effort, and time required by parents to provide such inclusion.

Physicians and parents agreed that children with severe disabilities are key family members. Most parents thought that their children unified and strengthened their families.

**Table 7.** Factors Influencing Health-Related Quality of Life

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Parent

*Inclusion*

- “She just wants to get out and interact with people and talk to them.”
- “Being treated like a person and not an object.”
- “Listen to music, go to school.”

*Staying on top of everything*

- “I am his medical coordinator.”
- “Need to care for themselves to provide for [their] child’s quality of life.”

Intern

*Inclusion*

- “Being able to get out and interact with other people.”
- “I think he’s happy with his family and that’s good enough for him.”

*Control or prevent complications*

- “Maximize his comfort and minimize the interventions.”

*Support family*

- “Coordinate with his parents and family.”

Hospitalist

*Focus on disability*

- “Issues of pain.”
- “Her seizure disorder.”
- “Her underlying static encephalopathy.”

*Minimize hospitalizations*

- “Keep him out of the hospital.”

*Support family*

- “Respect her mom’s wishes but also provide guidance about the future that I foresee for [the patient] but also try not to force my opinion on her.”

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Physicians appreciated the positive impact that children with severe disabilities had on their families generally and on their siblings specifically, but they were concerned about caregiver burden and the impact of caregiving on day-to-day family activities.

## DISCUSSION

Pediatric interns and attending hospitalists caring for children with severe disabilities during acute hospitalizations rated the child’s long-term HRQoL lower than did parents. Moreover, the themes identified during our qualitative interviews further support the clinical significance of these observed differences in parent and physician perceptions, which is consistent with the current literature.<sup>8,11,12</sup> Parent ratings of HRQoL have been shown to better align with the child’s self-ratings than with those of health care providers.<sup>10,11</sup> However, parents of children with chronic conditions actually rate their child’s HRQoL lower than do the children themselves.<sup>7,9</sup> It is possible that if our patients were able to self-report their HRQoL, they would have higher ratings than their parents, creating an even greater discrepancy between family and physician perceptions. Parents and their children generally differ on perceptions of internal states such as feelings of sadness or loneliness; however, our data indicated decreased agreement between parents and physicians in both ratings of function as well as internal states. This may relate to differences in how parents and physicians conceptualize HRQoL. HRQoL encompasses the health-related components associated with life satisfaction, such as self-care, mobility, and communication.<sup>21</sup> HRQoL is often confused with broader constructs of QoL, which encompass being (who one is), belonging (person’s fit with his or her environment), and becoming (purposeful activities carried out to achieve personal goals, hopes, and wishes).<sup>21</sup> Other researchers have reported that parents perceived negative messages about the care of their children with disabilities from physicians.<sup>22</sup> The ratings by physicians in our study seem to reflect beliefs regarding each child’s functional status and prognosis, whereas parent perceptions instead seem to reflect the broader QoL concepts.

QoL is an important construct when considering patient responses to illness and treatments over time, and frames discussions about treatment goals. QoL is best assessed by self-report, but when not possible, parents have been shown to be closest in ratings to their children and therefore are the preferred proxies. However, parent ratings are influenced by parenting stress,<sup>12</sup> suggesting that assessments be done when children are at baseline rather than during acute illnesses. QoL ratings also change across the course of an illness,<sup>8</sup> emphasizing the importance of longitudinal assessments. There are discrepancies in ratings of HRQoL between different professions,<sup>23</sup> and it has been hypothesized that the amount and timing of exposure to the child would influence perceptions of HRQoL.<sup>12</sup> Hospitalists only see children during acute illnesses rather than during their everyday lives. This might lead hospitalists to perceive HRQoL more negatively than they might if they

were able to see these children in better health and in the context of their families and communities.

Physicians are expected to prescribe medical interventions and therapies that improve health outcomes for their patients. This is especially true during acute hospitalizations when decisions regarding surgeries, assistive technologies, and end of life arise. Some physicians in our study commented that their care for children with severe disabilities may not have benefited the children but instead was rendered at the requests of parents. Most physicians thought that their primary role was to support families. Yet parents of children with disabilities thought that physicians focused on illnesses, hospitalizations, and caregiver burden, often considering the parents' expectations to be unrealistic.<sup>24</sup> Approaches that align treatment goals and expectations between parents and physicians regarding the acute inpatient care for children with severe disabilities might reduce communication gaps, increase satisfaction, and minimize readmissions.<sup>5</sup> Moreover, defining expectations is essential for strong parent-provider partnerships, a key element in the care of children with disabilities.<sup>25</sup>

Simon et al recommend that hospitalists implement high-quality processes around shared decision making with families, especially for preference-sensitive decisions.<sup>15</sup> When facilitating parent decision making on behalf of their children with disabilities, parents most need evidence-based, value-free information, time to talk to others, and control over the process.<sup>26</sup> Physicians in our study recognized the need to "try not to force [their] opinion" but demonstrated very different ideas about goals of care and benefits of interventions, which might bias information sharing when facilitating decisions. Physician self-awareness of their personal biases and the conveyance of evidence-based information to families can help keep conversations value-free. Decision tools such as written lay information on treatment options and associated risks and benefits of each should be provided to families, followed by adequate time for them to review the information and discuss options with others as needed. This approach has been shown to increase parental participation and communication, and decrease parent-provider conflict in shared decision-making processes.<sup>27</sup> It is important that parents trust their child's physician and care team, yet this can be limited in hospital settings where long-term relationships with providers are infrequent. In such scenarios, it may be beneficial to bring in physicians who know the child and family longitudinally to facilitate care planning.

This study has several limitations. The participants comprise a small sample from a single hospital and may not represent the general population. Enrollment only took place on weekdays, and children who were not cared for by both a hospitalist and intern were not eligible for inclusion in the study. This included many specialist teams and the trach/vent unit. Eligible patients were identified by senior residents, who may have had more negative perceptions of the child's abilities than if the patients had been identified by parents. However, we think that our sample is representative of the children admitted during this

time period. Second, this hospital-based study lacks the perspectives of community-based, primary care physicians who share a longitudinal view of the child's chronic illness and disability. Physicians only caring for the child while they are hospitalized are only able to view the child and their family during illness, which may contribute to a skewed view of the child's QoL. However, we think that this accurately represents the care teams that patients have during an acute hospitalization. Third, because HRQoL measures for children with disabilities are quite limited, we used the KIDSCREEN-10 as a proxy for physicians although it has only been validated for parents. We also extended the lower age range from 8 years to 5 years. This may have influenced findings, although, unlike previous researchers, we did not observe floor effects as parents and physicians rated the HRQoL of children with severe disabilities.<sup>12</sup> This suggests that KIDSCREEN-10 measured this construct effectively. However, children with severe disabilities under 5 years of age comprise an important group of children who are frequently hospitalized and are an important focus for future research. We also used a supplemental survey in addition to the KIDSCREEN-10 that was piloted on caregivers of children with severe disabilities but is not validated. Despite these limitations, we believe that the breadth and depth of this combined qualitative-quantitative appraisal of parent and physician perspectives of the HRQoL of children with severe disabilities offers significant insights for pediatric clinicians who are caring for these children and their families. Our findings may help physicians and parents come to a better understanding regarding treatment goals and expectations for the future, and help strengthen the parent-physician partnership.

## CONCLUSIONS AND IMPLICATIONS

Physicians rate the HRQoL of children with severe disabilities during acute hospitalizations lower than do their parents. Although parents of children with severe disabilities focus broadly on their QoL and express a hopefulness regarding the developmental potential of their children, physicians tend to focus on long-term health-related issues of morbidity and mortality. Physicians and parents have different goals and expectations during hospitalizations, with physicians often considering parents' expectations to be unrealistic. This may contribute to parent-provider communication gaps and recurrent admissions. Physicians caring for children with severe disabilities hospitalized for acute illnesses should explicitly discuss HRQoL and general QoL with parents at admission as well as periodically during prolonged stays. Providing hospitalists with information about the patients HRQoL before their hospitalization may help decrease discrepancies between parents and physicians. Physicians should be aware of their tendency to view the child's QoL as lower than the parents do, and they should try to appreciate the positive impact these children have on their families. Parents should be prepared to partner with physicians and provide input on their goals and long-term expectations for their children. This proactive

approach will strengthen parent–physician partnerships through shared expectations for management of the acute illness and anticipated outcomes at the time of discharge.

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### SUPPLEMENTARY DATA

Supplementary data related to this article can be found online at <http://dx.doi.org/10.1016/j.acap.2014.02.012>.

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