Quality of Health Care for Children

Role of Health and Chronic Illness in Inpatient Care Experiences

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Objective: To assess how parent reports about the inpatient care of their children vary according to the health status of children with and without chronic conditions.

Design: We analyzed parent responses to the Picker Institute Pediatric Inpatient Survey.


Participants: Overall, 12,562 parents of children who received inpatient care at participating hospitals.

Main Outcome Measure: Parent rating of overall quality of care.

Results: Fifty-one percent of parents reported that their child had a chronic condition. Quality-of-care ratings varied according to health status and the presence of chronic conditions. Parents of children in the worst (fair or poor) health without chronic conditions reported lower quality of care ($P < .001$) and more care problems ($P < .001$) than did those with chronic conditions. Parents of children in the best (excellent, very good, or good) health tended to rate care highly, whether or not their children had chronic conditions. In a multivariable model, the decrement in perceived quality of care associated with poorer health was greater for those without than for those with chronic conditions ($P < .001$).

Conclusions: Although children in poor health are at risk for experiencing a lower quality of health care, parents of such children who have chronic conditions report fewer care-related problems. This may be owing to the more frequent health care interactions and better continuity of care for children with chronic conditions.

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PATIENT REPORTS ABOUT HEALTH care experiences are increasingly being used to assess selected aspects of health care quality. When health care for children is evaluated, parents can report their own and their child’s experiences of care. The increasing use of patient and family reports is a result of the availability of valid and reliable survey instruments for such assessments and the belief that quality health care should reflect and be responsive to patient values. Patient reports of processes of care have also been linked to medical outcomes, reinforcing the importance of patient-centered care.

Patient characteristics, including health status, are associated with quality assessments; adult patients in poor health tend to report a lower quality of health care more often than healthier patients do. A similar relationship has been documented in the pediatric outpatient setting. Several explanations have been proposed for the association between health status and reports about quality of care. Sicker patients may have more complex medical needs and a greater need for communication and support. Reporting tendencies may also account for some of the association between self-reported health and problems with care. For example, if a person has a general tendency to give negative reports, then this tendency may influence reports about health status and health care experiences.

Like parents of children in poor health, parents of children with chronic conditions sometimes report a lower quality of care. Children with chronic conditions are more likely to be in poor health than chil-

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children without chronic illnesses, however, and the separate influences of health status and chronic conditions on patient reports of experiences are poorly understood.

The relationship between having a chronic condition and experiences with care may be different from the association between overall health status and health care experiences. The treatment of some chronic conditions can be relatively uncomplicated and straightforward. Other chronic conditions may be more medically complex or have a greater effect on daily life. Furthermore, persons with chronic conditions may not have the complex needs, including the need for increased information, of patients with other types of poor health. On the contrary, persons with particular chronic conditions may have less need for information because they have experience with the health care system and are knowledgeable about their condition. Thus, it may be possible to gain a more refined assessment of the quality of care by assessing the independent effects of chronic conditions and global health status on perceived quality of care.

In this article, we assess how parent reports about quality of pediatric inpatient care vary by parent-reported global health status for patients with and without chronic conditions. The Picker Institute Pediatric Inpatient Survey (PIS) was used to collect parent reports about 7 aspects of patient-centered care. In addition to examining how overall perceived quality of care differs by health status, we also assessed which aspects of health care are most salient for patients with and without chronic conditions and with different levels of self-reported health.

## METHODS

### DESIGN

We analyzed responses to the PIS, administered to randomly selected parents of children who had received inpatient care at participating hospitals.

### SITES

Thirty-nine hospitals voluntarily used the PIS for quality improvement purposes, as an independent quality improvement effort or because they participated in hospital consortia interested in these efforts. Participating hospitals included members of the University HealthSystem Consortium and National Association of Children’s Hospitals and Related Institutions. Hospitals that used the PIS were given data regarding their performance for quality improvement purposes and regarding the performances of other participating hospitals for benchmarking purposes.

### SAMPLE

Parents of children who were discharged after medical, surgical, or intensive care from participating hospitals within 6 weeks of the start of the survey cycle were eligible to participate. We used DataStat software (DataStat Inc, Ann Arbor, Michigan) to select 26,250 parents at random from the eligible population between January 1, 1997, and December 31, 1999. The survey was mailed to parents approximately 2 weeks after the child’s discharge from the hospital. A reminder postcard was mailed to nonresponding parents at 2 and 4 weeks after the original mailing.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Question</th>
</tr>
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<tbody>
<tr>
<td>Partnership between family and clinicians</td>
<td>did the doctors pay enough attention to your experiences and suggestions in caring for your child? Did you have liked more involvement in making the decisions about your child’s hospital care?</td>
</tr>
<tr>
<td>Coordination of care</td>
<td>Sometimes in the hospital, one doctor or nurse will say one thing, and then another will say something quite different. Did this happen during your child’s hospital stay?</td>
</tr>
<tr>
<td>Information to parents</td>
<td>Were the doctors available to answer your questions and concerns when you needed them? When you had important questions to ask the doctors, did you get answers you could understand?</td>
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<tr>
<td>Information to child</td>
<td>Was information about his or her condition discussed with your child in a way he or she could understand?</td>
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<tr>
<td>Physical comfort</td>
<td>Did the hospital staff do everything they could to help control your child’s pain?</td>
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<tr>
<td>Confidence and trust</td>
<td>Did you have confidence and trust in the doctors caring for your child?</td>
</tr>
<tr>
<td>Continuity and transition</td>
<td>Did someone on the hospital staff tell you what you needed to know to care for your child at home?</td>
</tr>
<tr>
<td>Overall quality of care</td>
<td>Overall, how would you rate the care your child received at the hospital?</td>
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## PEDIATRIC INPATIENT SURVEY

The PIS asked 62 questions about the following 7 aspects of care: partnership, coordination of care, information to parents, information to the child, physical comfort, confidence and trust, and continuity and transition. The survey also asked “Does your child have a chronic or long-term medical condition (a condition lasting longer than 3 months)” and additional questions about the parent’s primary language, race, and ethnicity. Parents were asked, “In general, would you say your child’s health is (excellent, very good, good, fair, or poor)?” Sample questions are displayed in Table 1 (the complete PIS is available from the authors on request). Variables used in the analyses presented herein include a global assessment of quality of care and dimension-specific problem scores. The global question asked parents to rate the care their child had received at the hospital overall, with response categories of poor, fair, good, very good, and excellent. Parents were asked, “In general, would you say your child’s health is (excellent, very good, good, fair, or poor)?” For example, in answer to the question, “Would you have liked more involvement in making the decisions about your child’s hospital care?” responses of “yes, definitely” and “yes, somewhat” were scored as problems, whereas the answer no was not. Dimension-specific problem scores for each parent were then calculated by determining what percentage of responses demonstrated problems with care. For questions about information given to the child, parents were given the option to state that the child was too young or could not understand such information; the dimension-specific problem score was therefore calculated among those parents who considered their children old enough and able to understand. The overall problem score was calculated as an average of problem scores of all dimensions.
Parent and patient characteristics are presented in Table 2. Of participating hospitals, 64% (n=25) were academic health centers, 13% (n=5) were freestanding children’s hospitals, and 62% (n=24) were privately owned. The proportion of participants who received care in each hospital type is presented in Table 2. The median number of beds was 434 (range, 48-1141).

Approximately half of the parents said that their children had a chronic health condition. Children with chronic conditions were more likely to have had surgery (28.85% vs 24.77%; P < .001) or an ICU admission (33.74% vs 29.81%; P < .001) than those without chronic conditions, and children with chronic conditions therefore accounted for more than half of all surgical or ICU admissions in the sample. Children with chronic conditions were also more likely to have received care at an academic medical center (79.41% vs 69.58%; P < .001).

Parent assessments of overall quality of care were converted to a quality-of-care score ranging from 0 (poor) to 100 (excellent) for these analyses. The parent quality-of-care score was used as the outcome variable in a multivariable linear regression model, with the patient as the unit of analysis. Analyses were performed using generalized estimating equations (the SAS GENMOD procedure; SAS Institute Inc, Cary, North Carolina) to account for clustering by hospital. A multivariate regression model was developed using backward elimination with confirmation by stepwise procedures. First, variables that have been previously described in the literature or that were believed to be clinically relevant (race, parent education, intensive care unit [ICU] admission, surgery during hospital admission, length of stay, and admission to an academic health center) were included in the model. Next, variables that had significant bivariate associations with the quality measures were considered for inclusion, with the threshold for entry into the model of P < .10 and for retention in the model of P ≤ .05. Variables considered for inclusion were problem dimension scores, parent-rated health status, and the presence of a chronic condition. To assess whether health status modifies the effect of patient or care attributes on ratings of quality of care, interaction terms between health status and each of the problem dimensions were also included in the models. Significant interactions (P ≤ .05) were retained in the models. Models were created using the entire sample and, subsequently, separate models were created for the children with and without chronic conditions. To facilitate the comparison of models, any variables that were significant (P ≤ .05) in one model were retained in both models. Interaction terms among the chronic condition variable, health status, and the problem dimension scores were created in the model for the entire sample to test whether coefficients differed significantly between the models for children with and without chronic conditions. We present the model for the entire sample, except where coefficients differ significantly between patients with and without chronic conditions. Where such differences exist, we present separate effect estimates for both populations. Analyses were conducted using the SAS statistical package (SAS Institute Inc).

Overall, 26,250 surveys were mailed, and 12,562 parents responded (overall response rate, 48%; range, 32%-59% by hospital). Data regarding nonrespondents were not available for analysis.

PARENT, PATIENT, AND HOSPITAL CHARACTERISTICS

The Dana-Farber Cancer Institute Office for the Protection of Research Subjects designated this secondary data analysis as being exempt from US federal requirements for approval by the institutional review board.

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by their parents than were those with chronic conditions (P < .001). Despite the prevalence of chronic conditions, however, nearly two-thirds of patients were rated by parents as being in very good or excellent health.

**QUALITY-OF-CARE RATINGS**

Most of the parents rated their child’s inpatient care as excellent (46.62%) or very good (31.73%), with the remainder rating the care as good (15.15%), fair (4.89%), or poor (1.60%). The quality-of-care rating varied according to parent-reported child health status, with parents of the healthiest children tending to give care the highest quality ratings (P < .001). Parents of children with chronic conditions gave more positive quality ratings overall than did parents of children without chronic conditions, after stratification by health status (P < .001). Parents whose children were in fair or poor health with nonchronic conditions reported the lowest quality of care. Parents of children in the best (excellent, very good, or good) health reported the highest quality of care, whether or not their children had chronic conditions. Parents of children with chronic conditions and fair or poor health reported intermediate quality of care, higher than the quality of care reported for those in similar health without chronic conditions, but lower than the quality of care reported for those in the best health (P < .001).

**PROBLEM SCORES**

Parents reported the most problems with health care in the areas of information to the child (mean problem score, 31.8%) for parents who considered their child old enough and able to understand such communication [n = 5128] and the parent-physician partnership (mean problem score, 29.8%). Across all measured dimensions of patient care, parent-reported child health status was strongly associated with the presence of problems in care, with more problems reported by parents of children in worse health (P < .001 for all problem dimensions).

Parents of children with chronic conditions reported fewer problems with care than did parents of children without chronic conditions for all care dimensions studied. The highest percentages of problems were reported by parents of children in fair or poor health without chronic conditions (Figure 1). When children in similar health had chronic conditions, parents tended to report fewer problems. The fewest problems were reported by parents of children in the best health, regardless of the presence of chronic conditions (P < .001).

**CORRELATION BETWEEN PROBLEMS AND OVERALL CARE QUALITY**

Parents who reported more problems in any dimension of care tended to give lower ratings for quality of care. Problems with information to parents (r = −0.60) and parent-physician partnership (r = −0.58) had the strongest associations with care ratings (data not shown).

**MULTIVARIABLE LINEAR REGRESSION MODELS**

Multivariable linear regression models in which the parent-reported quality-of-care score was the dependent vari-

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**Figure 1.** Overall problem scores according to health status and the presence of chronic conditions. Scores are described in the “Pediatric Inpatient Survey” subsection of the “Methods” section.
able indicated that problems in communication to the child were negatively associated with quality of care ratings for parents of children with chronic conditions (\(P = .02\)). They were not a significant factor for those without chronic conditions (\(P = .60\)). Child health status and problem scores in all other dimensions of care were significantly associated with overall quality-of-care ratings in both populations; the association between child health status and quality of care was stronger among those without a chronic condition (\(P < .01\)). Partnership was more closely associated with quality-of-care ratings among patients without chronic conditions (\(P < .01\)).

In this study of selected aspects of the care of hospitalized children, we found that children in the best health experienced fewer problems, whether or not they had chronic conditions. The association between reported overall health and perceived quality of care was greater for children with nonchronic conditions than it was for children with chronic conditions. For each category of worsening health, the gap between quality perceived by parents of children with and without chronic conditions widened.

The fact that children with chronic conditions reported better experiences than did other children, except for those in the best health, seems somewhat counterintuitive given the direction of the health status effect. The concern that children with a chronic condition might experience more care problems has been supported by previous studies documenting lower parent ratings of quality,3 greater difficulty in obtaining needed medical care,28 and more unmet needs for routine and specialty care28 among chronically ill children compared with children without chronic conditions. Socioeconomic,29 racial, and ethnic disparities30 contribute further to these differences. However, because children with chronic conditions tend to be in poorer health than other children, such comparisons often confound the effects of health and chronic conditions.

One possible explanation for why children with chronic conditions have better experiences is that children with special health care needs are more likely than healthier children to have continuity of providers in routine and sick care,28 a care attribute that has been linked to greater satisfaction with care and improved patient outcomes.31-33 Increased continuity appears to contribute to enhanced communication, including parents’ perceptions that providers listen to and respect them and that providers give understandable information.31 Although we do not know whether the chronically ill patients in our study also experienced greater continuity of care between their outpatient care and their inpatient stays, we speculate that this difference might in part explain these parents’ perceptions of higher quality of care and fewer care problems.

In previous studies, parents of children with chronic conditions have asserted that care should be developmentally appropriate, family centered, coordinated, technically competent, and interpersonally competent.34 Parents also emphasize the importance of receiving information related to the disease and its management.35 These should be the characteristics of the care for all hospitalized children and families, regardless of disease chronicity, but it may be that parents of children with chronic conditions are more effective at eliciting such care. Adolescents with chronic illness value direct communication from the physician, rather than through their parents.36 The relationship we found between communication with children and quality of care, seen specifically in children with chronic conditions, highlights this value.

This study raises questions about why children in poor health with nonchronic conditions experience so many care problems. This group probably includes children who have newly diagnosed serious conditions, or who are facing a severe acute illness. Parents of children with newly diagnosed conditions note that the stress of the diagnosis impairs understanding and retention of medical information.37 However, we found that communication and a sense of parent-physician partnership are among the processes of care most strongly correlated with overall quality-of-care ratings. The challenge of understanding and retaining information, coupled with the potential for increased information needs as parents learn about a new medical condition, may leave parents of children with nonchronic conditions feeling that their needs have not been met during a hospitalization. Conversely, parents of children with chronic conditions may already have a knowledge base about the child’s condition, making communication about the disease less fundamental to their ability to understand and cope with an illness and provide care for the child. These parents may also have had the opportunity to process information over a longer period, with ongoing conversations with long-term providers and greater use of other modes of information support.

An alternative explanation for the relationship between child health status and reported quality of health care is that problems in care cause poor health. Other authors have found that patients’ reports of processes of care are associated with long-term health outcomes of myocardial infarction.9 That study found problems to be associated with a relatively small decrement in overall health; however, whether the range of health states reported by parents in our study can be explained by lower quality of health care is unclear. If lower quality of health care explains poor
health, then distinct mechanisms could underlie differences in health between children with and without chronic conditions. Children with chronic conditions may be in poor health because of the natural trajectory of disease, whereas children without chronic conditions may have poor health that is caused by problems in care. Our data cannot address these hypotheses directly, but attention to other measures of health care quality such as actual health outcomes or adherence to evidence-based guidelines will be important in future research.

Another possible mediator of the health status effect is the length of hospital stay. Children in poor health may have more contact with the health care system and thus more opportunities for problems in care. However, adjustment for length of stay did not alter the effect of health status on quality ratings, making this hypothesis less likely.

The extent to which reporting tendencies explain the association between health status and reported quality of care remains unknown. However, the use of the chronic condition variable, which should be less subject to reporting tendencies, in combination with health status, allows an assessment of quality of care that delineates differing needs and experiences. The potential for clinical variability in the chronic condition variable and reported health status makes combined consideration an important aspect of quality assessment, with relevance to clinically meaningful health states. Without separate consideration of these subgroups, quality problems unique to these health states may not be detected.

Reports in the literature on quality of care for patients with chronic conditions have been inconsistent, possibly owing to the wide variation in clinical complexity and severity among those with these conditions. Studies in adult patients have found health status to be a more reliable marker of medical condition, including complexity. However, a study of parent-defined long-standing illness in children linked parent reports to actual health conditions, most commonly to congenital anomalies, asthma, and developmental delay, suggesting a reasonable clinical correlation between parent report and significant pediatric illness.

This study has several limitations. The parent response rate was 48%, and data on nonrespondents were not available for analysis. Although this response rate is comparable to those of similar studies, respondent bias is possible. In addition, although the sample of parents within each institution was randomly selected, participating hospitals conducted the survey because they wanted to use it for quality improvement efforts. This resulted in a sample heavily weighted toward academic health centers and, consequently, with a large proportion of patients treated surgically or in the ICU. This could affect the generalizability of our findings.

Children and families of children in poor health with nonchronic conditions deserve increased attention in future research so that unmet needs can be defined and interventions can be devised and tested. In addition, our clinical response should include efforts to recognize the potential for increased communication needs when conditions are newly diagnosed and to maintain continuity between inpatient and outpatient care. The initial diagnosis of a serious illness in a child can be devastating for the child and family; the experience of care should not increase this stress but should help families through this difficult time.

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REFERENCES


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