Quality of Care at a Children’s Hospital

The Parents’ Perspective

Charles J. Homer, MD, MPH; Barbara Marino, RN, PhD; Paul D. Cleary, PhD; Hillel R. Alpert, MPM; Barbara Smith, MBA; Constance M. Crowley Ganser, MS, RNC; Robert M. Brustowicz, MD; Donald A. Goldmann, MD

Objectives: To develop a measure of parental perceptions of pediatric inpatient quality of care, to identify processes of care that influence these perceptions, and to describe these perceptions of care.

Design: An interdisciplinary team modified an existing measure of inpatient care for adults using focus groups and expert review. The resulting survey was administered by telephone.

Setting: Tertiary care pediatric hospital.

Patients: Trained telephone interviewers obtained reports from parents of children discharged from the hospital during specified months. This report is based on the answers to 122 questions provided by 3622 (77%) of 4724 parents who responded when surveyed from 1991 through 1995.

Main Outcome Measures: Parents provided reports about specific clinical experiences, overall ratings of care, and patient demographic and illness characteristics 2 weeks after patient discharge from the hospital. The analysis classified reports about pediatric care as either problems or not problems. Problems in different areas of care were averaged to create scores for the dimensions.

Results: Parents most often noted problems related to hospital discharge planning (18%) and pain management (18%) and less often reported problems concerning communication about surgery (10%) or transmission of information to children (6%). Problems in communication between clinicians and parents correlated most strongly with overall quality ratings by parents ($r = 0.59$). Parents’ specific reports of problems with care accounted for 42% of the variation in their overall assessments of the inpatient care experience.

Conclusions: Parental assessment of inpatient pediatric care rests heavily on the quality of communication between the clinician and parent. Specific processes of care strongly influence overall assessments. Such reports could be used to focus the quality-improvement activities of hospitals and increase the accountability of providers of care to children and families.


Editor’s Note: I am struck by the finding that pain management was at the top (with hospital discharge planning) of problems most often noted by parents. Is this a form of child abuse that should be investigated?

Catherine D. DeAngelis, MD

Finding out how parents view their child’s hospital experience should be of great importance to hospitals caring for children in the current health care environment. Internal motivation, external regulation, and competitive pressure all compel hospitals and health care organizations caring for children to focus on improving the quality of care they provide.1,2 Because parental satisfaction is an important outcome of pediatric care, hospitals can try to identify and respond to the concerns of parents as one strategy in an overall program of quality improvement.1,4 Parents’ reports about their children’s care can also efficiently provide information about processes of care compared with resource-intensive methods such as medical record review or videotaping. Unfortunately, few practical measures of parental experience with pediatric inpatient care have been described.

The lack of focus on developing measures of parental experience with pediatric inpatient care may reflect the relative infrequency of hospitalization for the pediatric population. Only 3.6% of people younger than 18 years experience hospitalization in a year compared with 16.2% of adults older than 65 years. Nonetheless, pediatric hospitalization consumes approximately 44% of overall pediatric child expenditures and is likely to be highly salient for both children and their parents.5

From the Departments of Medicine (Drs Homer and Goldmann), Nursing (Dr Marino), Anesthesia (Dr Brustowicz), and Quality Improvement (Drs Homer, Marino, and Goldmann, Mr Alpert, Ms Smith, and Ms Ganser), Children’s Hospital, and the Departments of Pediatrics (Drs Homer and Goldmann) and Health Care Policy (Dr Cleary), Harvard Medical School, Boston, Mass.
We conducted 3 focus groups—with hospital medical staff, with nursing staff and management personnel, and with parents of children with chronic illness—to learn how these groups defined quality for children’s inpatient care. Project personnel compared field notes from these focus groups with dimensions used in the Picker/Commonwealth Patient Centered Care survey.11 The Picker survey is an instrument used to assess inpatient care for adults developed by a similar process; it emphasizes patient-provider communication, emotional support, involvement in decision making, and coordination of care. Based on this comparison, the survey team modified some items from the Picker survey and introduced new items and dimensions specific to pediatric care. The new dimensions specifically focused on communication with, and respect for, the child. Hospital administrative and clinical leaders reviewed items and identified those of highest institutional priority using a modified Delphi process.

The project team then developed a pilot instrument consisting of 175 items. This instrument was pilot tested with parents of 300 patients, and subsequently shortened by 53 questions to improve ease of administration. Of the remaining 122 items, 21 assess patient or respondent characteristics (including presence of a chronic condition, family income, and perceived general child health status) or prior health care. Six assess respondent attitudes about health care (eg, “Even if medical news is bad, a parent should be told about it”). Nine questions allow for open-ended response, typically following a “screening” question, such as “While [patient’s name] was in the hospital, was there anything that made you angry about the care?” followed by “What did you feel angry about?” The remainder of the questions are quite specific, intending to elicit reports about particular events or patterns of care during the hospitalization, eg, “Did you know which doctor was in charge of [patient’s name] care in the hospital?” and “Did the doctor explain the risks, benefits, and alternatives to treatment in a way that you could understand?” The survey was translated into Spanish, and the translation was verified through independent back-translation into English.

The survey is organized to follow the sequence of a typical patient’s experiences during the hospital stay. Initial questions examine how the patient was oriented to the hospital; later questions focus on performance of hospital discharge planning. Overall assessment questions follow the items assessing specific aspects of hospital care.

STUDY SAMPLE AND PROCEDURE

The survey was performed once a year in 1991 and 1992, each year covering patients discharged over a 2-week span with a target sample size of 300. Beginning in 1993, the survey was performed twice yearly, with the sample drawn from patients discharged over 4 consecutive weeks and target sample sizes of 600. The 1992 survey oversampled patients insured through Medicaid with a 2:1 sampling ratio.

The president of the hospital sent a letter to parents 1 week after patient discharge from the hospital explaining the purpose of the survey and informing the parent that they might be called. Trained interviewers using computer-assisted telephone interview equipment at an independent survey research firm administered the survey in either English or Spanish, depending on patient preference.

ANALYSES

Items that report on specific aspects of care are dichotomized as “problems” or “not problems.” For items with more than 2 response categories, the responses are considered to represent problems when any of the least preferable 2 of 4 or 3 of 5 categories are chosen (eg, “sometimes” or “never,” on a scale also including “usually” or “always”). The analysis grouped items into 6 broad dimensions of care—information to parents, information to the patient, partnership in care, pain management, surgical issues, and preparation for discharge from the hospital. These dimensions were derived from the initial focus groups and the Picker survey. Dimension scores are the number of problems within each dimension of care for a particular patient, divided by the number of possible items for that patient in that dimension, multiplied by 100. Changes in dimensions over time were assessed through linear regression, with the dimension score as the dependent measure and the year as the independent measure.

We calculated a summary rating of quality of care by computing the mean of 6 global ratings: courtesy and helpfulness of physicians; courtesy and helpfulness of nurses; availability of physicians; availability of nurses; coordination of care; and overall care.12 Associations between dimension scores and the summary rating were assessed with Pearson product moment correlation and linear regression.

We defined a dimension impact score to provide a measure that incorporates both the frequency of the problems within a dimension and the importance of those problems to patients.13 To calculate this score, the independent contribution of each dimension to the overall ratings of care was determined with linear regression. The value of the coefficient for each dimension was multiplied by the dimension score and multiplied again by the number of respondents who responded to any of the items in the dimension. For ease of interpretation, the products were converted to a 100-point scale by dividing each score by the total of the scores, and then multiplying by 100. This number conveys the relative priority of the dimensions for choosing areas for improvement but has no absolute meaning and cannot be compared across surveys.

The impact of the case mix was assessed by including demographics (race, education) and illness (presence of chronic condition, global health status) as independent measures in a linear regression model along with dimension scores (with the overall assessment as the outcome measure) and comparing the model $r^2$ with that for the model of the dimension scores alone.

Researchers examining health services for children have long studied the determinants of parental satisfaction with pediatric physician services, particularly with care delivered in ambulatory settings. These studies have shown that parental satisfaction with outpatient care is strongly influenced by the clinician providing clear information to the parent that addresses parental concerns and by demonstrating sensitivity to the parent’s emo-
Of 4934 families initially targeted for inclusion, 210 were not eligible because their primary language was neither English nor Spanish. Of the remaining 4724, 465 (10%) could not be reached, 236 (5%) refused, and 401 (8.5%) could not complete the survey during the time period. Overall, 3622 (77%) of the eligible families completed the survey. Response rates did not vary significantly by year. A parent served as the respondent in 3477 cases (96%), and either the legal guardian or another relative served as the respondent for the remainder. A high proportion of respondents were college educated (Table 1).

Parents consistently reported that problems occurred most often in the areas of hospital discharge planning and pain management (Table 2). Parents often noted that they had neither been taught how to give medicines (23% [512 of 2224]) nor told what adverse effects to check for after their children went home (25% [537 of 2149]). More than two thirds of the time, parents reported that caring for their child after discharge from the hospital was either more or less difficult than they had been told to expect (71% [2512 of 3538], with 34% [1203] more difficult and 37% [1309] less difficult), and almost half of the time parents reported the staff was not very helpful with their worries about home care (46% [321 of 697]). One third of parents (834 of 2527) indicated that their child’s pain during the hospital stay was substantially different from what they were advised to expect. Twenty-six percent of parents (779 of 2998) judged the response to a call for pain control insufficiently prompt.

Parents reported the fewest problems in the areas of surgery and the conveyance of information directly to the child. Parents (1760 of 1815) met with their child’s surgeon and discussed risks, benefits, and alternatives more than 95% of the time; similarly, parents reported receiving clear information about the results of surgery in almost all cases (1772 of 1808). Problems were more frequent in the provision of emotional support around the time of surgery, with almost 20% of parents (181 of 1005) indicating their child did not have the opportunity to discuss fears about surgery, and a somewhat higher proportion of parents not having had such an opportunity. Despite the relatively high proportion of children who were not given the chance to discuss fears, parents in general raised few other concerns about communication between hospital personnel and their children. Parents almost universally reported that their children were treated with respect and dignity and that explanations to their children about procedures were clear. Far fewer than 10% of parents reported their child was upset by a clinician failing to self-identify to their child (7% [127 of 1817]) or by using words that were difficult to understand (2% [30 of 1488]).

Although problems in hospital discharge planning remained among the most common through 1995, these reports diminished significantly since the start of the survey in 1991 ($t = -7.16, P<.001$). No other areas changed significantly during the 4-year period (Table 3).

Problems with information to parents correlate most strongly with parents’ overall ratings of quality ($r = 0.59$), followed by issues related to the partnership between the family and care providers ($r = 0.51$) (Table 4). Information transfer to the patient and communication about surgery are least strongly associated with parents’ overall assessments. Taken together, the 6 dimensions

---

Table 1. Characteristics of Patients and Telephone Interview Respondents*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patient or Respondent, No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>English speaking</td>
<td>3173 (88)</td>
</tr>
<tr>
<td>Patient age, y</td>
<td></td>
</tr>
<tr>
<td>&lt;1</td>
<td>935 (26)</td>
</tr>
<tr>
<td>1-5</td>
<td>1049 (29)</td>
</tr>
<tr>
<td>5-10</td>
<td>712 (20)</td>
</tr>
<tr>
<td>10-17</td>
<td>926 (25)</td>
</tr>
<tr>
<td>Patient sex, M</td>
<td>2048 (57)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>2521 (77)</td>
</tr>
<tr>
<td>Black</td>
<td>364 (11)</td>
</tr>
<tr>
<td>Asian</td>
<td>74 (2)</td>
</tr>
<tr>
<td>American</td>
<td>31 (1)</td>
</tr>
<tr>
<td>Other</td>
<td>291 (9)</td>
</tr>
<tr>
<td>Reported patient health</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>1250 (35)</td>
</tr>
<tr>
<td>Very good</td>
<td>900 (25)</td>
</tr>
<tr>
<td>Good</td>
<td>881 (25)</td>
</tr>
<tr>
<td>Fair</td>
<td>423 (12)</td>
</tr>
<tr>
<td>Poor</td>
<td>139 (4)</td>
</tr>
<tr>
<td>Presence of a chronic condition</td>
<td>1741 (51)</td>
</tr>
<tr>
<td>Parental education</td>
<td></td>
</tr>
<tr>
<td>Did not graduate from high school</td>
<td>391 (11)</td>
</tr>
<tr>
<td>Completed high school</td>
<td>1050 (29)</td>
</tr>
<tr>
<td>Completed college</td>
<td>1636 (45)</td>
</tr>
<tr>
<td>Completed graduate school</td>
<td>532 (15)</td>
</tr>
<tr>
<td>Income, $</td>
<td></td>
</tr>
<tr>
<td>&lt;15 000</td>
<td>764 (23)</td>
</tr>
<tr>
<td>15 000-49 999</td>
<td>1505 (46)</td>
</tr>
<tr>
<td>≥50 000</td>
<td>1087 (31)</td>
</tr>
<tr>
<td>Underwent surgery during hospital stay</td>
<td>1821 (51)</td>
</tr>
<tr>
<td>Length of hospital stay, h</td>
<td></td>
</tr>
<tr>
<td>&lt;48</td>
<td>1629 (45)</td>
</tr>
<tr>
<td>48-96</td>
<td>874 (24)</td>
</tr>
<tr>
<td>&gt;96</td>
<td>1119 (31)</td>
</tr>
</tbody>
</table>

* The total number of respondents was 3622.
<table>
<thead>
<tr>
<th>Dimension, Score</th>
<th>Respondents</th>
<th>No. for Whom Question Applicable</th>
<th>No. (%) With Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information to parents, 13.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Told patient's daily routine early on</td>
<td>3500</td>
<td>1155 (33)</td>
<td></td>
</tr>
<tr>
<td>Physicians available to answer your questions</td>
<td>3555</td>
<td>995 (28)</td>
<td></td>
</tr>
<tr>
<td>Nurses available to answer your questions</td>
<td>3569</td>
<td>714 (20)</td>
<td></td>
</tr>
<tr>
<td>Consistency of information from providers</td>
<td>2994</td>
<td>479 (16)</td>
<td></td>
</tr>
<tr>
<td>Told whom to ask for help</td>
<td>3565</td>
<td>428 (12)</td>
<td></td>
</tr>
<tr>
<td>Amount of information about patient's condition or treatment</td>
<td>3595</td>
<td>360 (10)</td>
<td></td>
</tr>
<tr>
<td>Upsetting information given sensitively to patient</td>
<td>926</td>
<td>93 (10)</td>
<td></td>
</tr>
<tr>
<td>Answers you could understand from physicians about patient</td>
<td>3597</td>
<td>288 (8)</td>
<td></td>
</tr>
<tr>
<td>Answers you could understand from nurses about patient</td>
<td>3602</td>
<td>252 (7)</td>
<td></td>
</tr>
<tr>
<td>Staff called you when necessary</td>
<td>3498</td>
<td>245 (7)</td>
<td></td>
</tr>
<tr>
<td>Tests and procedures explained so you could understand</td>
<td>1728</td>
<td>52 (3)</td>
<td></td>
</tr>
<tr>
<td>Explanations of medications used in the hospital</td>
<td>3619</td>
<td>108 (3)</td>
<td></td>
</tr>
<tr>
<td>Information to patient, 5.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information given to patient about condition</td>
<td>1790</td>
<td>286 (16)</td>
<td></td>
</tr>
<tr>
<td>Tests and procedures explained so patient could understand</td>
<td>690</td>
<td>69 (10)</td>
<td></td>
</tr>
<tr>
<td>Patient upset because it was not explained what provider was to do</td>
<td>1811</td>
<td>145 (8)</td>
<td></td>
</tr>
<tr>
<td>Patient upset because provider did not explain who they were</td>
<td>1817</td>
<td>127 (7)</td>
<td></td>
</tr>
<tr>
<td>Patient was told something you did not want them to know</td>
<td>1808</td>
<td>90 (5)</td>
<td></td>
</tr>
<tr>
<td>Upsetting information given sensitively to patient</td>
<td>1481</td>
<td>59 (4)</td>
<td></td>
</tr>
<tr>
<td>Patient treated with respect and dignity</td>
<td>3317</td>
<td>100 (3)</td>
<td></td>
</tr>
<tr>
<td>Patient could understand information given about condition</td>
<td>1488</td>
<td>30 (2)</td>
<td></td>
</tr>
<tr>
<td>Partnership, 13.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confidence and trust in primary nurse</td>
<td>3563</td>
<td>641 (18)</td>
<td></td>
</tr>
<tr>
<td>Involvement in decisions about patient's hospital care</td>
<td>3504</td>
<td>631 (18)</td>
<td></td>
</tr>
<tr>
<td>Confidence and trust in physician in charge of patient's care</td>
<td>3561</td>
<td>641 (18)</td>
<td></td>
</tr>
<tr>
<td>Amount of your participation in patient's care</td>
<td>3570</td>
<td>536 (15)</td>
<td></td>
</tr>
<tr>
<td>Knew who was the primary nurse</td>
<td>3593</td>
<td>503 (14)</td>
<td></td>
</tr>
<tr>
<td>Knew who was the physician in charge of patient's care</td>
<td>3590</td>
<td>467 (13)</td>
<td></td>
</tr>
<tr>
<td>Enough providers' attention to your experience, suggestions</td>
<td>3574</td>
<td>250 (7)</td>
<td></td>
</tr>
<tr>
<td>Parent treated with respect and dignity</td>
<td>3317</td>
<td>133 (4)</td>
<td></td>
</tr>
<tr>
<td>Pain management, 17.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amount of pain experienced differed from what told to expect</td>
<td>2527</td>
<td>834 (33)</td>
<td></td>
</tr>
<tr>
<td>Quick enough response to call button</td>
<td>2998</td>
<td>779 (26)</td>
<td></td>
</tr>
<tr>
<td>Pain medication received fast enough</td>
<td>1918</td>
<td>192 (10)</td>
<td></td>
</tr>
<tr>
<td>Appropriate amount of pain medication given</td>
<td>2593</td>
<td>182 (7)</td>
<td></td>
</tr>
<tr>
<td>Hospital staff sensitive to patient's pain</td>
<td>2606</td>
<td>104 (4)</td>
<td></td>
</tr>
<tr>
<td>Surgery, 9.9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents' fears or anxieties about surgery discussed</td>
<td>1809</td>
<td>362 (20)</td>
<td></td>
</tr>
<tr>
<td>Patient's fears or anxieties about surgery discussed</td>
<td>1005</td>
<td>181 (18)</td>
<td></td>
</tr>
<tr>
<td>Enough time to discuss anesthesia risks, benefits, and alternatives</td>
<td>1800</td>
<td>396 (17)</td>
<td></td>
</tr>
<tr>
<td>Risks, benefits, and alternatives to anesthesia were discussed</td>
<td>1804</td>
<td>289 (16)</td>
<td></td>
</tr>
<tr>
<td>Surgery results explained in a way patient could understand</td>
<td>1007</td>
<td>121 (12)</td>
<td></td>
</tr>
<tr>
<td>Enough time to discuss risks, benefits, and alternatives to surgery</td>
<td>1812</td>
<td>127 (7)</td>
<td></td>
</tr>
<tr>
<td>Anesthesia explained before the procedure</td>
<td>1806</td>
<td>108 (6)</td>
<td></td>
</tr>
<tr>
<td>Parent met with surgeon</td>
<td>1818</td>
<td>73 (4)</td>
<td></td>
</tr>
<tr>
<td>Risks, benefits, and alternatives to procedure were discussed</td>
<td>1815</td>
<td>54 (3)</td>
<td></td>
</tr>
<tr>
<td>Results of surgery explained in a way parent could understand</td>
<td>1808</td>
<td>36 (2)</td>
<td></td>
</tr>
<tr>
<td>Hospital discharge planning, 18.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amount of home care required different from what expected</td>
<td>3538</td>
<td>2512 (71)</td>
<td></td>
</tr>
<tr>
<td>Helpfulness of staff with worries about home care</td>
<td>697</td>
<td>321 (46)</td>
<td></td>
</tr>
<tr>
<td>Told about adverse effects of medication to watch for</td>
<td>2149</td>
<td>537 (25)</td>
<td></td>
</tr>
<tr>
<td>Taught how to give patient medication</td>
<td>2224</td>
<td>512 (23)</td>
<td></td>
</tr>
<tr>
<td>Adequate time discussing home care with physician</td>
<td>3586</td>
<td>681 (19)</td>
<td></td>
</tr>
<tr>
<td>Hospital assisted prior to hospital discharge to get extra help at home</td>
<td>768</td>
<td>115 (15)</td>
<td></td>
</tr>
<tr>
<td>Told about patient activity limitations</td>
<td>3587</td>
<td>502 (14)</td>
<td></td>
</tr>
<tr>
<td>Told enough about how patient would feel at home</td>
<td>3582</td>
<td>466 (13)</td>
<td></td>
</tr>
<tr>
<td>Told about danger signals to watch for</td>
<td>3584</td>
<td>430 (12)</td>
<td></td>
</tr>
<tr>
<td>All helpful information about home care discussed</td>
<td>3291</td>
<td>329 (10)</td>
<td></td>
</tr>
<tr>
<td>Adequate time discussing home care with physician</td>
<td>3590</td>
<td>323 (9)</td>
<td></td>
</tr>
<tr>
<td>Taught what you needed to know to care for patient at home</td>
<td>2960</td>
<td>178 (6)</td>
<td></td>
</tr>
<tr>
<td>Told when to see a physician for follow-up</td>
<td>3004</td>
<td>150 (5)</td>
<td></td>
</tr>
<tr>
<td>Told whom to call with questions or concerns</td>
<td>3005</td>
<td>120 (4)</td>
<td></td>
</tr>
</tbody>
</table>

*Dimension score indicates mean number of reported problems in each dimension for all survey rounds.*
account for 42% of the variance in the summary rating of quality of care.

Patient experience and ratings of care did differ with illness and demographic characteristics. Patients with chronic conditions, in poorer health status, of low income, minority, non–English speaking, and those not undergoing a surgical experience all rated the care lower and indicated more problems across most dimensions of care (data available from C.J.H.). In this population, overall health status and minority status remained independent correlates of these outcomes, controlling for the other characteristics. Including the patient and illness characteristics only explained an additional 5% of the variability in parents' overall assessments beyond that provided by the dimensions alone.

When frequency and importance of problems are jointly considered in the dimension impact score, information transfer to parents emerges as the highest priority for improvement. Hospital discharge planning, pain management, and partnership with families are of intermediate priority; and problems related to information to the patient and surgical issues have the least need for targeted improvement activities (Table 4).

We have elicited parental reports about their child’s pediatric inpatient care as a component of our institutional quality measurement and quality improvement activities. We found that parents report problems most commonly in the areas of hospital discharge planning and pain management and least often in surgical communication and information to the child. Parents’ overall assessments of care are influenced most by the parents’ communication with hospital clinical staff and by the extent to which staff and parents are engaged in partnership. Parents who rated their child’s health lower, as well as disadvantaged and minority parents, reported more problems and rated pediatric care lower than did other parents. Despite the relative infrequency of problems with parental communication, this area is the highest priority when both frequency and importance to parents are considered. The reports have been stable over time, with concerns in only one dimension, hospital discharge planning, showing significant improvement. Patient and illness characteristics explain relatively little of the variability in parents’ overall assessments beyond that provided by the dimensions alone.

When frequency and importance of problems are jointly considered in the dimension impact score, information transfer to parents emerges as the highest priority for improvement. Hospital discharge planning, pain management, and partnership with families are of intermediate priority; and problems related to information to the patient and surgical issues have the least need for targeted improvement activities (Table 4).

**Comment**

We have elicited parental reports about their child’s pediatric inpatient care as a component of our institutional quality measurement and quality improvement activities. We found that parents report problems most commonly in the areas of hospital discharge planning and pain management and least often in surgical communication and information to the child. Parents’ overall assessments of care are influenced most by the parents’ communication with hospital clinical staff and by the extent to which staff and parents are engaged in partnership. Parents who rated their child’s health lower, as well as disadvantaged and minority parents, reported more problems and rated pediatric care lower than did other parents. Despite the relative infrequency of problems with parental communication, this area is the highest priority for improvement when both frequency and importance to parents are considered. The reports have been stable over time, with concerns in only one dimension, hospital discharge planning, showing significant improvement. Patient and illness characteristics explain relatively little of the variability in parents’ overall assessments of care after accounting for the specific inpatient experience.

The approach outlined here has methodological limitations. While the response rate is excellent, any incomplete response from a sample can bias the results. Prior studies have indicated that nonrespondents to satisfaction surveys tend to have somewhat less favorable views of their care than do respondents but demonstrate the same rankings of concerns. This study was done at a single academic tertiary institution, potentially limiting the generalizability of study findings. Nonetheless, this approach should apply to other such institutions, although the precise findings at other institutions would differ, depending on the pediatric care experience and
patient characteristics of that institution. The relatively high educational level of respondents in our study might also limit generalizability, although this level is characteristic of other Boston-based studies, and educational level per se was not an independent predictor of care experience.

We have demonstrated the feasibility of eliciting feedback from parents about the care that is provided at one tertiary care, academic pediatric hospital. What accounts for the excellent performance of care in some areas and the higher frequency of problems in others? We can speculate that communication regarding surgery is, in general, predictable, and the expectations and requirements for communication are well delineated. This predictability allows for the development of relatively straightforward systems and routines that meet family needs. In contrast, responding to a patient’s pain or planning for hospital discharge may be highly contingent on the individual needs of specific patients and families. Designing systems and training staff to best address such contingent situations is necessarily more difficult. In addition, pain management and especially hospital discharge planning typically involve more than one discipline and more than one system (e.g., ambulatory, home care, or school-based services). Such interdependent care needs are more difficult to coordinate.

The relatively few problems parents identified concerning clinical communication with children likely reflects the emphasis on child-centered care characterizing a pediatric institution. In addition, parents may feel that they can communicate with their children about medical care if communication with the parent was sufficient. Parents seem to be reporting that their needs would be best met in programs that are family centered and that emphasize communication with and support for parents as well as for children.

The association between poor health status and poorer care experience is consistently found throughout the English-language literature on patient satisfaction. This association may be in part methodological, i.e., persons who rate health lower may be more critical raters and parent-reported health status is generally well correlated with other markers of child health, such as hospitalization or the presence of chronic conditions. More likely, parents of children in poorer health likely have greater exposure to the health care system and greater expectations and needs from that system.

The association between markers of social disadvantage and health care experience have been less consistent in the English-language literature. Many, but not all, studies demonstrate less levels of satisfaction among poor and minority health consumers. Such ratings may also be confounded by different cultural expectations for health care and different interpretations of rating scales and assessments. In this study, these data suggest that there is a need in this institution for attention to care delivered to minority and disadvantaged populations but that attention to the major domains of care in the survey will account for most of the variation in care experience.

Care improved substantially in only one dimension, hospital discharge planning, over the period reported here. During this time the hospital undertook substantial initiatives in this area. A new staff role (the “patient care coordinator”) was created specifically to focus on hospital discharge planning from the time a patient is admitted. The hospital’s largest managed care partner (Harvard Pilgrim Health Care, Brookline, Mass) also created a full-time position focused on the hospital discharge process. The nursing staff undertook institution-wide training programs covering hospital discharge preparation. While opportunities for improvement remain, and the attribution of the improvement to one particular approach is not possible, the change shown in this dimension likely reflects actual improvements in care rather than random variation.

Data from this survey are reported back to each inpatient unit and hospital department. Recently, these reports have highlighted the relative performance of each unit and have named the unit with the fewest problems in each dimension. Our impression is that those individual programs that have incorporated these data into their quality improvement activities and have made substantial changes in program operation based on the findings have been able to show substantial improvement. However, strong incentives and expectations about addressing the concerns raised in the survey have not been applied consistently. This relatively weak accountability, as well as the inherent difficulty in changing matters as complex as communication and support, may explain the limited change in the other dimensions over time.

For our institution, these data point to the need for improvement in clear communication with parents as well as in the domains of partnership between hospital and parents, pain management, and hospital discharge planning. More broadly, these data reinforce the need for clinicians and institutions serving children to recognize that there are dual patients in pediatric care—both the actual patient and the parent(s). Families play an essential role in the health of children, and excellent pediatric care must be family as well as child centered. At least from the perspective of the parent, in complex inpatient settings as well as in ambulatory care, clear communication addressing the parents’ concerns remains the cornerstone of good quality of care. Providing a measurement system such as this introduces accountability of a hospital to the goals of family-centered care, focuses efforts on improvement, and monitors the progress of these efforts toward meeting these goals.

Accepted for publication April 15, 1999.

We acknowledge the ongoing support of the Children’s Hospital administration and of Michael Epstein, MD, and Eileen Sporing, RN, MSN, in particular, for this activity as well as technical support from Beth Katcher in Information Services in the conduct of the survey. We also thank Judith Palfrey, MD, for her thoughtful review of an earlier draft of the manuscript.

Corresponding author: Charles J. Homer, MD, MPH, National Initiative for Children’s Healthcare Quality, Institute for Healthcare Improvement, 135 Francis St, Boston, MA 02215 (e-mail: chomer@ihi.org).
REFERENCES