Hospitalized Children’s Perspectives on the Quality and Equity of Their Nursing Care

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Hospitalized children and adolescents (n = 496), aged 6 to 21 years, were asked to evaluate the quality of their nursing care by describing nurse behaviors that they liked and disliked. They named 1673 positive nurse behaviors (12 categories) that made them feel good, happy, safe, and cared about, including “gives me what I need when I need it” (42.3%) and “checks on me often” (34.7%). Six categories of negative nurse behaviors (n = 485), such as “does things to me that hurt or are uncomfortable” (64.1%) and “wakes me up” (24%), made them feel sad, bad, mad, scared, or annoyed. Key words: children, disparities, equity, hospitalization, nurse behaviors, quality of nursing care

APPROXIMATELY 3 million children in the United States are hospitalized every year,1,2 and many experts agree that the quality of care delivered to children by the current health system is inadequate.3,4 The Institute of Medicine reports that race, ethnicity, socioeconomic status (SES), age, and gender are genetic, biologic, and environmental constructs that may account for access, quality, and outcomes of health care.5 Unequal treatment is partly a result of providers’ biases. A widely accepted indicator and component of quality health care is patient satisfaction, typically measured by surveys mailed to patients’ homes after discharge from the hospital. In pediatrics, “patient” satisfaction surveys address the parents’ experiences with care. For example, parents are asked to evaluate, “your experience during your child’s most recent stay at the hospital” or “the services you and your child received from our facility.” Children are not routinely asked to evaluate their care during hospitalization or after discharge although children as young as 5 to 6 years can provide reliable and valid reports on their own health-related perceptions.6 At any age, illness threatens children’s sense of well-being, and hospitalization threatens their sense of security, independence, and self-control.7 Children’s positive and negative perceptions of their hospitalization experience are also influenced by their illness, invasive treatments, medications, and length of stay.7

Nurses provide care, comfort, and support to children 24 hours a day. The quality of pediatric nursing care is evaluated in many ways, including the hospital’s performance on nursing-sensitive indicators,8 medical record
and performance audits, and parent satisfaction surveys that address their experience with caregivers’ technical care, service, attitudes, and communications. In this study, we measured the quality of pediatric nursing care from the children’s perspective by eliciting their perceptions of positive and negative nurse behaviors that they experience during hospitalization. The aims of this cross-sectional descriptive study were to (1) identify nurse behaviors that matter most to 6- to 21-year-old pediatric patients during their hospitalization; (2) examine relationships between children’s perceptions of nurse behaviors and their current, physical, and emotional status; and (3) evaluate demographic differences for evidence of equity or disparity in children’s perceptions of nurse behaviors.

BACKGROUND

Judgments about satisfaction with care and quality of care are a function of the individual’s perceived need for care, expectations of care, and actual experience of care. Since 2004, 8 studies about children’s perceptions of their hospitalization experiences were conducted in Finland, England, and the United States, 5 of which were conducted by Pelander and colleagues from Finland. Some used projective techniques such as drawings of their “ideal hospital” (n = 40), sentence completion (n = 388), and storytelling in response to drawings of children in the hospital (n = 93). In the latter study, their stories described the children in the drawings as feeling alone, scared, mad, sad, bored, and lonely, although the frequency of these responses was not reported. It is notable that none of the emotions were positive.

In 3 studies, from 40 to 129 children were interviewed or completed brief open-ended questionnaires about their experiences. Two articles reported 388 children’s responses to a 58-item “child care quality at hospital” survey in which 5 items described nurse characteristics and 25 items described nurse behaviors. In nearly all of these studies, children made positive comments about nurses who were kind, friendly, and caring, made the children feel more comfortable, were entertaining, listened to the children, and explained things to them. Despite the fact that pediatric hospitals admit patients up to 21 years, most of the children were aged 4 to 11 years, except for 2 studies that included adolescents up to the age of 14 and 18 years. Nurse behaviors that were more important to older children were a positive attitude, advocacy and privacy, and reassurance, while younger children, especially school-aged, were more interested in being entertained by their nurses. Adolescents were most likely to mention that they appreciated nurses who afforded them respect and privacy. Children who had previous hospitalizations were more likely to mention entertainment and being acknowledged as an individual than those who had not been hospitalized before. With 2 exceptions, children were asked about their experiences several weeks after discharge rather than during their hospitalization. The potential influence of illness acuity and length of stay on children’s perceptions were not examined in these studies nor have researchers addressed racial, ethnic, SES, or gender differences in hospitalized children’s experiences with nurses and nursing care.

METHODS

Design and sample

We used a cross-sectional descriptive design to acquire quantitative and qualitative data from the children. The target population was 6- to 21-year-old hospitalized children and adolescents. For brevity, the generic terms “children” or “participants” are used throughout this article. The participants were selected from a 354-bed freestanding children’s hospital. Inclusion criteria were admission to the hospital, chronological age of 6 to 21 years, developmental age of at least 6 years, and English speaking. Power analysis for sample size was based on the number of subjects required to identify differences of 25% between group proportions at alpha = 0.01.
Our research team determined that a raw difference of 20% to 25% between 2 proportions would be clinically important; the arcsine transformation of this difference translates to a medium effect size ($h = 0.50$). The largest set of comparisons was between 5 age categories; thus, a total sample size of at least 465 subjects was needed.

Between 2007 and 2009, research assistants (RAs) explained the study to 557 hospitalized children and their parents, and 500 (89.8%) patients participated in the study. In 52 cases, parents did not approve of their child’s participation either because there was no time before being discharged or because they believed that the child was too ill or tired to participate. Four of the children were inadvertently interviewed twice and were removed from the analysis, leaving 496 participants.

**Instruments**

From medical records and parent report, we collected demographic data (age, sex, ethnic group, race, and zip code), information about previous hospitalizations, current diagnoses, the number of invasive procedures that children experienced prior to the interview (a proxy for illness acuity), and length of stay. Family zip codes and census tract data were used to estimate median household income and the percent of residents with incomes below the poverty line as proxies for SES. Physical and emotional status at the time of the interview were measured by the Pediatric Quality of Life-Present Functioning Scale (PedsQL-PF) and the Revised Children’s Depression and Anxiety Scale (RCADS). The 6-item PedsQL-PF scale measures children’s “present, at-the-moment functioning” relative to their current levels of fear, sadness, anger, worry, fatigue, and pain. In collaboration with its developer, the response options were changed from a visual analog scale of 0 to 100 to a 5-point scale (e.g., “I am (not) afraid or scared,” in which 1 = not, 2 = just a little, 3 = more than a little, 4 = very, and 5 = extremely). As a visual reference, a smiley face, sober face, and frowning face were equally spaced across the scale. Item scores were not totaled; rather, scores on each item were analyzed independently.

The RCADS consists of 47 items, for example, “I worry about things,” scored on a 4-point ordinal scale of 0 = never to 3 = always. Raw scores are converted to standardized T-scores according to sex and grade in school (grades 3-12+). A T-score of 65 or more is considered clinically significant. Alpha coefficients of the total scale and 7 subscales ranged from 0.71 to 0.85 with various community and clinical samples, and correlations with the children’s depression inventory ($r = 0.65-0.80$) and the Spence Children’s Anxiety Scale ($r = 0.65-0.82$) demonstrated construct validity. The Cronbach $\alpha$ for this sample ranged from 0.74 to 0.94.

On the basis of previous research studies and the research team’s clinical experience, the investigator-developed Hospitalized Children’s Structured Interview was used to elicit information about the children’s hospital experiences. Children’s responses to 2 of the questions related to nurse behaviors are reported here: (1) What do you like most about your nurses and what they do for you, and how does that make you feel? (2) What don’t you like about your nurses and what they do for you, and how does that make you feel?

**Procedure**

The institutional review board from the hospital research institute approved the study. Each week, RAs visited the hospital’s 16 nursing units in a randomized order on day and evening shifts. The RCADS and PedsQL were administered followed by the interview questions. To ensure that all participants received the same information, RAs verbally presented each instrument item and interview question to the participants. Research assistants documented the 6- and 7-year-olds’ responses and allowed the older children to record their own responses if they wanted to do so.

**Analysis**

To synthesize the nurse behaviors that mattered most to hospitalized children, one
investigator inductively sorted the children’s responses to the structured interview questions into mutually exclusive categories. Two investigators independently sorted a randomly selected 10% of the responses; interrater agreement of the category coding system was 92%. The dependent variable in all analyses was the proportion of children who endorsed a particular positive or negative nurse behavior. Independent variables included nominal-level demographic groups (eg, sex, race) and ordinal- or interval-level variables (eg, anxiety scores, the number of invasive procedures). To evaluate differences in children’s perceptions of each nurse behavior according to each independent variable, we used SPSS\textsuperscript{22} version 19.0 statistical program to calculate $z$ tests with Bonferroni corrections for between group proportions and independent-groups Mann-Whitney $U$ tests depending on the level of data.\textsuperscript{23}

**RESULTS**

**Sample characteristics**

The participants ranged in age from 6 to 21 years (mean $= 12.9$, SD $= 4.1$) and were nearly equally divided between males (49.1%) and females (50.9%). Developmental age groups included young school-aged (6-8 years; n = 99, 20%), older school-aged (9-11 years; n = 97, 19.6%), young adolescent (12-14 years, n = 102, 20.6%), middle adolescent (15-17 years; n = 123, 24.8%), and older adolescent (18-21 years; n = 75, 15.1%). The racial distribution was 73% White (n = 362) and 20.2% Black (n = 100). The most common diagnoses were gastrointestinal disorders (n = 128, 25.8%) followed by neurologic (n = 62, 12.5%), hematologic/oncologic (n = 54, 10.9%), and pulmonary disorders (n = 52; 10.5%). It was the first hospitalization for 184 (37.1%) of the children. Forty percent (n = 199) were interviewed on the day they were discharged; the others were interviewed on their second to 337th hospital day. It was the first hospitalization for 184 (37.1%) of the children.

**Positive and negative nurse behaviors reported by hospitalized children**

Participants provided 1673 responses to the question of “what do you like most?” All children named at least 1 nurse behavior that they liked (range $= 1-9$, mode $= 4$). The responses were inductively sorted into 12 categories as shown in the Table. The top-6 categories were as follows: gives me what I need when I need it, checks on me often, talks and listens to me, is nice and friendly to me, gives me medicine, and gives me things to do. When the children experienced these 12 nurse behaviors, they felt good, happy, safe, comfortable, or not bored. A persistent theme throughout was that they felt like the nurses cared about them. All but 5 of the participants responded to the question about nurse behaviors that they did not like, 137 of whom said that there was "nothing" they did not like about their nurses. The remaining 354 children reported a total of 485 behaviors they did not like (range $= 1-4$, mode $= 1$). Responses were inductively sorted into 6 categories (Table). Nearly two-thirds of the children did not like it when nurses do things to them that hurt or are uncomfortable (n = 85; 64.1%). Other common responses were "wakes me up," typically for vital signs, to check on them, or for medications, and "doesn’t give me what I need when I need it" such as attention, medication, or snacks. Children said that the negative nurse behaviors made them feel sad, bad, mad, scared, or annoyed.

Mann-Whitney $U$ tests indicated that the positive and negative nurse behaviors did not differ significantly according to the length of time that children were in the hospital at the time of their interview (1-337 days, median $= 4$), the number of invasive procedures that children experienced prior to the interviews (0-216, median $= 3$), or the number of previous hospitalizations (0-720, median $= 1$).

**Differences in children’s perceptions according to physical and emotional status**

Children’s self-reports on the PedsQL-PF indicated that feeling "somewhat, quite a bit,
Hospitalized Children’s Perspectives on Quality of Their Nursing Care

Table. Children’s Perceptions of Positive and Negative Nurse Behaviors

<table>
<thead>
<tr>
<th>Positive nurse behaviors</th>
<th>n (%)</th>
<th>How This Makes Me Feel</th>
</tr>
</thead>
<tbody>
<tr>
<td>(N = 496 respondents)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gives me what I need when I need it</td>
<td>210 (42.3)</td>
<td>Secure, like they really care, like I am important, happy</td>
</tr>
<tr>
<td>Checks on me often</td>
<td>172 (34.7)</td>
<td>Good, safer, that nurse cares about me</td>
</tr>
<tr>
<td>Talks, listens to me</td>
<td>163 (32.9)</td>
<td>At ease, very important, like they care about me, good</td>
</tr>
<tr>
<td>Nice, friendly</td>
<td>158 (31.9)</td>
<td>Happy, not so nervous, that I am special</td>
</tr>
<tr>
<td>Gives me medicine</td>
<td>144 (29.0)</td>
<td>More comfortable, safe, less pain, like I will get well</td>
</tr>
<tr>
<td>Gives me things to do</td>
<td>142 (28.6)</td>
<td>Happy, not bored, very happy</td>
</tr>
<tr>
<td>Helps me do things</td>
<td>100 (20.2)</td>
<td>That they care about me, happy, like I am the best patient</td>
</tr>
<tr>
<td>Takes care of me</td>
<td>87 (17.5)</td>
<td>Good, secure, better about being here</td>
</tr>
<tr>
<td>Makes me comfortable</td>
<td>82 (16.5)</td>
<td>Good, a lot better, as if they really care about me</td>
</tr>
<tr>
<td>Laughs and jokes with me</td>
<td>60 (12.1)</td>
<td>Great, happy, like I’m not a kid or just a regular patient</td>
</tr>
<tr>
<td>Plays with me</td>
<td>54 (10.9)</td>
<td>Really happy, good</td>
</tr>
<tr>
<td>Gives me respect and privacy</td>
<td>34 (6.9)</td>
<td>Like they care about my sleep, important</td>
</tr>
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<table>
<thead>
<tr>
<th>Negative nurse behaviors</th>
<th>n (%)</th>
<th>How This Makes Me Feel</th>
</tr>
</thead>
<tbody>
<tr>
<td>(N = 354 respondents)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does things to me that hurt or are uncomfortable</td>
<td>206 (58.5)</td>
<td>Kind of scared, pain, hurt, mad, uncomfortable</td>
</tr>
<tr>
<td>Wakes me up</td>
<td>85 (24.0)</td>
<td>Mad and tired, not very happy, tired and dizzy</td>
</tr>
<tr>
<td>Doesn’t give me what I need when I need it</td>
<td>67 (18.9)</td>
<td>Bad, mad, like they don’t care about me</td>
</tr>
<tr>
<td>Doesn’t talk or listen to me</td>
<td>25 (7.1)</td>
<td>Annoyed, frustrated, irritated</td>
</tr>
<tr>
<td>Not nice or friendly</td>
<td>25 (7.1)</td>
<td>Sad, scared, kind of sad and mad</td>
</tr>
<tr>
<td>No respect or privacy</td>
<td>19 (5.4)</td>
<td>Exposed, aggravated, like they don’t respect me</td>
</tr>
</tbody>
</table>

*tests for differences between proportions across age groups significant at 0.01 or less.

Young and older school-aged and young adolescents more than middle and older adolescents.

Young and middle adolescents more than other age groups.

Middle and older adolescents more than other age groups.

Young and older school-aged more than other age groups.

or very much” tired was the most common symptom (n = 165, 33.3%), followed by pain or hurt (n = 130, 26.2%), worried (n = 104, 21%), sad or blue (n = 48, 9.7%), afraid or scared (n = 37, 7.5%), and angry (n = 29, 5.9%). Children who reported that they liked nurses who “play with me” were significantly less tired (M = 0.89, SD = 0.97) than children who did not mention that behavior (M = 1.3, SD = 1.1) (P = .005). None of the other positive or negative nurse behaviors were related to the 6 PedsQL-PF symptoms.

T-scores on the RCADS anxiety and depression subscales ranged from 24 to 93, and mean and median scores ranging from 41 to 41.9 were clinically within normal
limits (<65). The number of children with T-scores in the clinically significant range was most notable for separation anxiety (n = 52, 10.5%), depression (n = 31, 6.3%), and panic disorder (n = 26, 5.2%). Children whose nurses “did not give me what I need” (M = 49.9, SD = 8.3) had higher panic disorder T-scores than children who did not mention that nurse behavior (M = 49.7, SD = 10.3 (P = .006). Higher scores on obsessive-compulsive, total anxiety, and total anxiety/depression subscales were observed among children who reported the negative nurse behavior of “doesn’t talk or listen to me” (M = 50.6-52.3; SD = 9.1-10.9) more often than their counterparts (M = 42.9-43.1, SD = 9.1-10.9) (P < .002).

Demographic equity and disparity of children’s perceptions of nurse behaviors

For comparisons across racial groups, only White (n = 362, 73%) and Black groups (n = 100, 20.2%) were analyzed because of insufficient numbers of other racial groups. There were no significant differences in perceptions of positive or negative nurse behaviors between White and Black children or between boys and girls. The median household income ranged from $14,718 to $95,618 (sample median = $37,967). According to Mann-Whitney U tests, children from low-income neighborhoods mentioned that the negative nurse behavior “wakes me up” more often than children who did not mention that behavior (P = .006). The positive nurse behavior “gives me things to do” was reported more often by children in neighborhoods with the highest percentage of incomes below the poverty line (P = .005).

Although most differences in proportions of nurse behaviors among the 5 age groups were not statistically significant, several behaviors showed age-related trends (Table). “Gives me things to do,” “plays with me,” “gives me medicine,” and “does things to me that hurt or are uncomfortable” were more important to the 2 school-aged groups than to the adolescent groups. Nurse behaviors that were more important to middle and older adolescents included “talks and listens to me” and “laughs and jokes with me.”

DISCUSSION

This study is the first to systematically elicit hospitalized children’s and adolescents’ views on the quality of their nursing care with simultaneous measurement of their current physical and emotional status and the first to evaluate children’s perceptions of nurse behaviors for evidence of equity and disparity across demographic groups. A cross-sectional research design maximized the diversity of the sample characteristics. Many of the 12 positive and 6 negative nurse behaviors identified by this diverse group of 496 children were similar to nurse behaviors reported in previous studies, despite differences in geographical area, methodology, and age of the participants, which suggests that these observations are universal across hospitalized children. A strength of the study was that the data were collected from children who were in various stages of their hospitalization to capture potential differences in children’s perceptions according to the length of time they were in the hospital prior to their interview. These findings suggest that nurse behaviors that are important to children are similar at any point in their hospitalization.

Validity of these findings is supported by developmentally consistent age-related trends in the relative importance of certain nurse behaviors. Children aged 6 to 11 years seek out their peers for play and interaction. During hospitalization when peers and parents are not available, school-aged children appreciate nurses who give them things to do and play with them. Adolescents aged 15 to 21 years are becoming more introspective and aware of their mortality and were most appreciative of nurses who took the time to talk and listen to them. At the same time, these adolescents still enjoyed a laugh or a joke with their nurses, perhaps to relieve their anxieties, or just for fun. Children felt that their
nurses cared about them; this was a recurring theme across all of the positive nurse behaviors. Feeling cared about is commonly associated with other important feelings that may influence the outcomes of care, such as feeling happy, comfortable, safe, less nervous, and important.

Hospitalized children want nurses who demonstrate a positive attitude and are interactive with them. Most of the negative nurse behaviors not only were the opposite of these but also included being awakened at night and being subjected to painful and uncomfortable procedures. As expected, more than half of the children disliked the painful and uncomfortable procedures that were inevitably required to treat their illnesses. While most procedures cannot be avoided, the manner in which they are carried out can be modified. For example, some children commented that nurses did not use a skin anesthetic prior to needle sticks, instilled intravenous medications too fast, pushed too hard during abdominal assessments, or pulled tape off the skin too fast. Unfriendly nurses made the children feel sad, mad, and scared. Sometimes pediatric nurses need to be reminded that many children are hospitalized for the first time (37% of this sample) and are lonely and frightened of the strange environment and people who interact with them each day.

With few exceptions, children’s reports of both positive and negative nurse behaviors were equally distributed across sex, race, and socioeconomic indicators. There was no evidence of bias or unequal treatment. This study was conducted in a Magnet hospital, recognized by the American Nurses Credentialing Center for nursing excellence, which may have diminished the number and variety of negative nurse behaviors that children identified. The hospital has child life staff that play an important role in keeping children busy and comfortable. The children were not likely to confuse them with nurses because their uniforms are different and nurses ensure that every child knows the name of “his or her nurse.”

CONCLUSIONS

The Institute of Medicine defines quality patient care from the consumer’s perspective as safe, timely, beneficial, patient-centered, equitable, and efficient.26 In response to open-ended questions, the participants in this study described positive nurse behaviors in these same categories: “checking on me often” made them feel safe, “giving me what I need when I need it” represented timely and efficient care, “helps me do things,” and “gives me medicine” were beneficial, and “talks and listens to me” indicated patient-centered care. The National Priorities Partnership, convened by the National Quality Forum, sets priorities to minimize health care disparities, harm, and waste.27 The first priority is patient and family engagement, which requires that “all patients will be asked for feedback on their experience of care, which health care organizations and their staff will then use to improve care.”27(p19) Satisfaction with care not only is a benchmark that hospitals use for regulatory and marketing purposes but also translates to clinical, behavioral, and emotional outcomes of care.9

Hospitalization can be a formative experience for children. Children’s positive or negative memories of their hospitalization experiences may influence their future attitudes toward health care, utilization of health care services, and career decisions. Nurses make a difference in the quality of children’s hospitalization experiences. Development of child-friendly assessment tools on quality of nursing, physician, and hospital care is feasible and should be a priority. We believe that pediatric patients should have systematic opportunities to evaluate the quality of their care during hospitalization and other types of health care visits. Nurses should be held accountable for timely and appropriate responses to the children’s concerns about their care and for communicating them to other staff. Research is needed to evaluate the link between children’s perspectives on the quality of their care and the outcomes of their care.
REFERENCES


