RESEARCH ARTICLE

Understanding Parental Preferences for Participants in Medical Decision-making for Their Hospitalized Children

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ABSTRACT

OBJECTIVES: Family-centered care promotes parental engagement in medical decision-making for hospitalized children. Little is understood about parental preferences and factors influencing the desire to involve extended family in decision-making. We explored parent and family member interest in participation in medical decision-making.

METHODS: Parents of hospitalized children ≤7 years old admitted to the inpatient service were interviewed regarding preferences for self-, other parent, and extended family involvement in decision-making. Scores were calculated for each potential participant on a scale of 1 to 5 (5 indicating that parents strongly agreed with participation). Associations of decision-making preferences with parental age, education, language, and health; the involvement of a child with chronic illness; and the level of clinical acuity were assessed with χ² tests, Wilcoxon rank tests, and the Spearman correlation.

RESULTS: There were 116 participants. Parents’ median level of interest in participation in decision-making was as follows: self (4.3; interquartile range [IQR]: 4–4.6); other parent (3.6; IQR: 2.7–4), and family (2.0; IQR: 1.7–2.7). Parents with better physical health (P < .001) and those in a relationship with the other parent (P < .001) were more likely to desire involvement of the other parent in medical decision-making. This was also true for those who faced higher acuity scenarios. Parents <35 years old (P < .01) and those who were interviewed in Spanish (P = .03) were more likely to desire participation of extended family members.

CONCLUSIONS: Parents of hospitalized children want to participate in medical decision-making. Desire for the involvement of other family members is complex; therefore, discussions regarding parental preferences are necessary.

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Dr Dadlez conceptualized and designed the study, conducted the analyses, and drafted the initial manuscript; Dr Bisono and Ms Williams participated in data collection, reviewed data and analyses, and revised the manuscript; Drs Rosenthal and Hametz conceptualized and designed the study, reviewed data and supervised analyses, and critically revised the manuscript; and all authors approved the final manuscript as submitted.
We hypothesized that demographic factors and previous experience with the health care system (due to personal health issues or children with complex medical issues) would similarly influence parental preferences in decision-making for their children. We also explored how the level of clinical acuity (ie, severity of illness) would influence preferences on who would be the primary decision-maker.

METHODS

Study Population

Participants were recruited as a convenience sample of parents of children on the inpatient service at a children's hospital within an urban academic medical center between February 2013 and July 2013. The inpatient service provides care to a mix of general pediatric and subspecialty patients, with subspecialties including gastroenterology, hematology, hepatology, pulmonology, endocrinology, infectious diseases, metabolic and genetic diseases, and nephrology. Study participants met the following eligibility criteria: they had to be parents of children <7 years old admitted to the inpatient service for >2 days and had to be Spanish or English-speaking. We included only children who were too young to participate in decision-making to focus on parental preferences without the need to consider the patients’ preferences. Families of patients who were being evaluated for potential child maltreatment were not approached.

Informed, written consent was obtained from each parent, and each parent received $25 as compensation for their time. This study was approved by the Columbia University Medical Center Institutional Review Board.

Study Design

A 30- to 45-minute survey was administered orally in Spanish or English by a bilingual research coordinator. The Decision-making Preference Scale portion of the Autonomy Preference Index was modified to make it applicable to the parents of pediatric patients and to elicit parental preference for participation of self, other parent, and extended family members in medical decision-making. This portion of the survey used respondents’ rating of agreement with 3 statements measuring the preference for participation of each potential participant (self, other parent, other family member) in decision-making on a 5-point Likert scale, with 1 indicating strong disagreement and 5 indicating strong agreement. A mean score of the 3 ratings was calculated to assess the overall preferences for each potential participant.

To assess for predictors of parental preferences, the survey included questions on participant demographic data and family structure. Parents were queried about the current relationship with the other parent, and for the purposes of this study, we defined being in a relationship as living with or married to the other parent. The Patient-Reported Outcome Measurement Information System (PROMIS) physical and mental health scale, a standardized assessment tool, was used to evaluate the self-reported health of the parent respondent. The PROMIS scales generate a T-score, which is standardized to a national mean of 50 with an SD of 10. A concomitant chart review was conducted on each patient to assess factors hypothesized to have an association with parental decision-making preferences that were not captured in the survey, including insurance status and the presence of significant chronic illness. Significant chronic illness was defined as a patient meeting any of the following criteria: ≥3 chronic diagnoses, the use of daily medications other than treatments for asthma or gastroesophageal reflux disease, or being technology dependent.

In addition, parents were given 2 clinical scenarios developed by the research team. These scenarios were piloted with a small group of parents of hospitalized children before the study to ensure relevance and comprehensibility. Each scenario was of differing clinical severity and was used to ask the respondent who should make the...
medical decision regarding treatment of their child. If parents did not provide a primary decision-maker they were prompted with the following: “you, the other parent, another family member, the doctor, or someone else?” The first scenario (Box 1) involved the decision of whether to place an intravenous (IV) catheter in case it was needed and the second involved the decision of whether to place a chest tube in a child with pneumonia and effusion (Box 2). This segment was designed to see how parents would react in medical encounters with different levels of risk associated with the treatment decision. Additionally, this gave them an opportunity to identify who they would select as the primary decision-maker(s) for their child in response to an open-ended question. These scenarios were chosen because they are common decisions that need to be made in pediatric hospital medicine and because there is not a clear right or wrong answer. To eliminate pain as a possible confounder regarding decision-making, both scenarios involved a potentially painful procedure.

**Box 1**

Michael is in the hospital because he is having severe headaches. Right now, he can eat, drink, and take all of his medicines by mouth. But there is a chance that, during the night, he will need medicine or fluids through an IV. There is a team of nurses whose job it is to put IVs in kids; they are only here during the day. There is a choice: the team can put the IV in now, just in case Michael needs it overnight, or you can wait. If he needs it overnight, Michael will have to be woken up, and it may be a little more uncomfortable if someone who is less experienced than the day person has to put the IV in. Who should make the choice about whether to place the IV now or wait?

**Box 2**

Michael is in the hospital and has been sick with pneumonia. The radiograph reveals that he has infected fluid around his lung. There are two options for treatment. The first option is to do surgery to put in a chest tube. The chest tube would drain the infected fluid, and he would feel better quickly. The doctors explain that he would be uncomfortable from the chest tube. There is also a chance of serious side effects, although those would be treatable. The other option is to give antibiotics and hope that the fluid goes away by itself. Without surgery, it would take longer for his breathing to get better. There is a chance that the fluid would not go away by itself and that he might need surgery later anyway. Who should decide whether to do surgery to place the chest tube or to wait?

**Statistical Analysis**

Descriptive statistics of the sample characteristics were conducted by using univariate analysis and frequency tables. Mean scores were calculated from the Likert scale questions for parental preference for participation of self, other parent, and extended family members in medical decision-making on the basis of responses to modified version of the Autonomy Preference Index.32 Scores were not normally distributed; therefore, medians are reported and nonparametric tests were used when appropriate. Bivariate analyses were conducted to look for variables associated with scores for each individual’s participation in decision-making. For responses to the clinical scenarios, results were analyzed in 3 categories of potential decision-makers, which composed the 3 majority groups: mother, both parents, or other individuals. Continuous variables were assessed for normality. Data were analyzed by using χ² tests when assessing associations of 2 categorical variables, Wilcoxon rank tests when assessing associations of categorical and continuous variables, and the Spearman correlation when assessing associations of 2 continuous variables. Because the authors posited that parental relationship status may be an effect-modifier with respect to physical health, a multivariable linear regression was performed with the “other parent” score as the dependent variable and parental relationship status, physical health and an interaction term as the dependent variables. Statistical analyses were performed by using SAS (SAS Institute Inc, Cary, NC) and Stata 13.0 (StataCorp, College Station, TX). The α criterion was set at P < .05.

**RESULTS**

**Study Population**

On days that the research team was enrolling participants, there were a total of 265 hospitalized patients whose parents met study criteria; 116 were enrolled and all completed the study. The participants were mostly mothers, 33% had a high school education or less, 28% were <24 years old when the child was born, 22% were 35 years or older, and 32% completed the interview in Spanish (Table 1). For physical and mental health, the mean T-scores were 51.7 and 52.2 respectively. The children had a mean age of 2 ± 2 years, and 43% had significant chronic illness.

**Participants in Decision-Making**

Parents agreed that they themselves should participate in medical decision-making (99% agreed or strongly agreed). Seventy-three percent agreed or strongly agreed that the child’s other parent should participate in decision-making. If the child’s illness were to worsen, 76% of parents agreed or strongly agreed that they would want to take “greater control” in decision-making and 43% agreed or strongly agreed that the other parent should take greater control. More than half (67%) of respondents did not want to involve extended family members in medical decision-making for their children. Parents’ median level of agreement with each participant’s involvement in decision-making on the modified Autonomy Preference Index Scale was as follows: self: 4.3 (interquartile range [IQR]: 4–4.6),
were more likely to desire extended family members: 2.0 (IQR: 1.7–2.7), and extended family members: 2.0 (IQR: 1.7–2.7).

Factors Associated With Parental Preferences

Parents uniformly wanted to be involved in their child’s care. There were no predictors of self-involvement (Table 2). Parents who had greater physical health (Table 2) and those who were in a relationship with the other parent (3.7 (IQR: 3.3–4.7) vs 3.0 (IQR: 2.3–3.7); $P < .001$) were more interested in the participation of the other parent of the child. In a multivariable analysis, parent physical health was an independent predictor of interest in the participation of the other parent, and this was not influenced by parental relationship status (interaction term $P = .73$).

Parents had mixed preferences on the choice to involve extended family members in medical decision-making for their children (Table 2). Spanish-speaking parents were more likely to desire extended family involvement in medical decision-making when compared with English-speaking parents. Parental age was significantly associated with a desire for extended family involvement: older parents were less likely to want extended family to participate in medical decisions for their children. The level of education, medical complexity of the child’s condition, and respondent’s health were not significantly associated with parental preferences.

**Acuity**

The 2 scenarios were analyzed according to the desired primary decision-maker(s) (ie, mother, both parents, and other decision-maker) identified by the parent respondent. The higher-acuity situation involved an increased risk of side-effects or treatment failure associated with the decision compared with the lower-acuity situation.

Responses were analyzed according to the 3 majority groups: mother, both parents, and other. The other category responses were diverse and included inpatient doctor, subspecialist, extended family members, and patient’s primary care physician. When compared with the low-acuity situation, parents in the high-acuity situation were 3 times more likely to want both parents of the child involved in the medical decision-making and less likely to identify the mother alone or another decision-maker ($P < .001$; Fig 1).

**DISCUSSION**

Parental involvement in medical decision-making for hospitalized children is an integral part of effective family-centered care on the pediatric inpatient service; however parents may have differing preferences on the degree of involvement. Because family structures are changing, and relatives often play a role in child care and support for parents during their child’s hospitalizations, physicians are challenged to explore who should be involved in the decision-making process. In previous research, patients in our cohort unanimously wished to participate in decision-making for their hospitalized children. Lipstein et al found that the majority of parents of children with juvenile idiopathic arthritis reported using family or friends to inform decision-making regarding therapeutic options. In our cohort, these responses were more discordant; two-thirds of parents did not desire involvement of extended family members in medical decision-making for their children. This was particularly true
of older parents who may have been more self-reliant in their abilities to make decisions regarding their child. On the other hand, a third of parents did desire the involvement of extended family members in medical decision-making. We found that Spanish-speaking parents had a stronger preference for extended family member participation in medical decisions for their children compared with non-Spanish-speaking parents. Although this may be related to unmeasured cultural factors, another possible explanation is that parents who are primarily Spanish-speaking may feel more comfortable having an English-speaking family member involved in medical decisions, despite the availability of translator services. In a study by Seltz et al. in 2011, the authors found that Hispanic families were often dissatisfied with telephonic interpretation services and did not feel empowered to request interpretation or health information for their children. Additionally, parents in Seltz et al.’s study reported that they felt embarrassed by their inability to understand English. In our survey, we did not assess whether the family members whom the parent wanted to include were English-speaking. Further research is necessary to explore the motivations behind these preferences and optimize communication strategies with Spanish-speaking families.

In daily clinical practice, the inclusion of extended family members may also vary on the basis of who is present at the bedside and providers’ presumptions of the parent’s wishes. Although many physicians may ask the parent which family members they would like to have remain at the bedside for medical discussions, this is not done universally. Additionally, providers may not ask parents if they would desire extended family member involvement if the other family members are not immediately present. Determining the parent’s preference on who should be privy to medical discussions about the child, including those not immediately at the bedside, could mitigate this difficulty. Addressing these issues early in the admission process may allow the team to include the appropriate parties when decisions regarding the child’s care plan arise. Involving other family members in discussions may, however, pose logistical challenges, and the feasibility of this is an area for further study as well.

Our study has several limitations. It was conducted by using a convenience sample from 1 hospital and may not represent the full spectrum of parents of hospitalized children. We were unable to assess parental motivations for the preferences reflected in their responses and how past experiences influenced their choices. Additionally, our survey did not explore custodial arrangements and whether the other members in discussions may, however, may allow the team to include the appropriate

### TABLE 2: Associations With Parental Desire for Involvement of Participants in Decision-Making (*N = 116*)

<table>
<thead>
<tr>
<th></th>
<th>Self</th>
<th>P</th>
<th>Other Parent</th>
<th>P</th>
<th>Extended Family</th>
<th>P</th>
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<tbody>
<tr>
<td>Parent age, y&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>25</td>
<td>4.5 (4.0–4.7)</td>
<td>.95</td>
<td>3.3 (2.5–4.0)</td>
<td>.21</td>
<td>2.3 (2.0–3.0)</td>
<td>.01*</td>
</tr>
<tr>
<td>25–35</td>
<td>4.3 (4.0–5.0)</td>
<td>.95</td>
<td>3.3 (2.7–4.0)</td>
<td>.21</td>
<td>2.3 (1.7–2.7)</td>
<td>.01*</td>
</tr>
<tr>
<td>35</td>
<td>4.3 (4.0–4.7)</td>
<td>.95</td>
<td>3.7 (3.3–4.0)</td>
<td>.21</td>
<td>2.0 (1.3–2.0)</td>
<td>.01*</td>
</tr>
<tr>
<td>Survey language&lt;sup&gt;a&lt;/sup&gt;</td>
<td>.80</td>
<td>.97</td>
<td></td>
<td>.04*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spanish</td>
<td>4.3 (4.0–4.7)</td>
<td>.80</td>
<td>3.7 (2.3–4.3)</td>
<td>.97</td>
<td>2.3 (2.0–2.7)</td>
<td>.04*</td>
</tr>
<tr>
<td>English</td>
<td>4.3 (4.0–5.0)</td>
<td>.80</td>
<td>3.3 (3.3–4.7)</td>
<td>.97</td>
<td>2.0 (1.3–2.7)</td>
<td>.04*</td>
</tr>
<tr>
<td>Highest level of education&lt;sup&gt;a&lt;/sup&gt;</td>
<td>.68</td>
<td>.22</td>
<td></td>
<td>.22</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than a high school diploma</td>
<td>4.3 (4.2–4.7)</td>
<td>.68</td>
<td>3.3 (2.3–4.3)</td>
<td>.22</td>
<td>2.3 (2.2–2.7)</td>
<td>.22</td>
</tr>
<tr>
<td>High school graduate</td>
<td>4.3 (4.0–5.0)</td>
<td>.68</td>
<td>3.7 (3.0–4.0)</td>
<td>.22</td>
<td>2.3 (2.0–3.0)</td>
<td>.22</td>
</tr>
<tr>
<td>Some college</td>
<td>4.3 (4.0–4.6)</td>
<td>.68</td>
<td>3.3 (2.7–4.0)</td>
<td>.22</td>
<td>2.0 (1.3–2.7)</td>
<td>.22</td>
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<tr>
<td>College graduate or more</td>
<td>4.7 (4.0–5.0)</td>
<td>.68</td>
<td>3.5 (3.0–4.0)</td>
<td>.22</td>
<td>2.0 (1.7–2.3)</td>
<td>.22</td>
</tr>
<tr>
<td>Child has a significant chronic illness&lt;sup&gt;a&lt;/sup&gt;</td>
<td>.91</td>
<td>.14</td>
<td>.45</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Yes</td>
<td>4.3 (4.0–5.0)</td>
<td>.91</td>
<td>4.0 (3.3–4.7)</td>
<td>.14</td>
<td>2.3 (1.7–2.7)</td>
<td>.45</td>
</tr>
<tr>
<td>No</td>
<td>4.3 (4.0–4.7)</td>
<td>.91</td>
<td>4.0 (3.7–4.7)</td>
<td>.14</td>
<td>2.0 (1.7–2.7)</td>
<td>.45</td>
</tr>
<tr>
<td>Parent physical health&lt;sup&gt;b&lt;/sup&gt;</td>
<td>–0.07</td>
<td>.45</td>
<td>0.34</td>
<td>&lt;.001*</td>
<td>.03</td>
<td>.73</td>
</tr>
<tr>
<td>Parent mental health&lt;sup&gt;b&lt;/sup&gt;</td>
<td>–0.14</td>
<td>.14</td>
<td>0.15</td>
<td>.11</td>
<td>–0.14</td>
<td>.14</td>
</tr>
</tbody>
</table>

<sup>a</sup> Median involvement score (IQR).

<sup>b</sup> Spearman ρ correlation coefficient.

* P < .05.
parent or extended family had legal guardianship of the child in question. We were also unable to assess other ways in which parents may seek support from extended family for medical decision-making without taking an active role in the discussion. In addition, the way in which family dynamics and nonmedical burdens factor into decision-making is another area for future study. We examined bivariable associations and were therefore unable to account for potential confounders. Finally, because we focused on young children in an urban tertiary care center with a high case mix index that practices family-centered care, the results may not generalize to other settings.

Family-centered care and the involvement of parents in medical decision-making for their children is considered the standard of care in pediatrics. Variation may exist in how clinicians present decisions to families, and time constraints may prompt some providers to involve whichever parent and/or family member is present at the bedside during points of decision-making. However, some parents may desire the involvement of the other parent or extended family members. Conversations about participation in decision-making should happen early in the admission and may need to be revisited, especially if the child’s condition worsens or the decisions become increasingly complex. Future qualitative studies may elucidate parental motivations for decisions regarding the involvement of other family members in medical decision-making for their hospitalized children.

CONCLUSIONS

Parents of young hospitalized children want to participate in medical decision-making. However, their desire for the involvement of other family members is more complex. Parental health status and experience with the health care system may be factors associated with that preference. Assumptions should not be made about which relatives the parent would like to involve in decision-making. Rather, discussions with parents regarding preferences for involvement of extended family members in medical decision-making are necessary to respect their wishes and provide truly family-centered care.

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