Pediatric Hospitalists’ Perspectives on the Care of Children With Medical Complexity

abstract

OBJECTIVE: The aims of this study were to identify pediatric hospitalists’ perceived views of (1) barriers to delivering care to children with medical complexity (CMC) and (2) their preferred model of inpatient health care delivery for CMC.

SUBJECTS: American Academy of Pediatrics Section on Hospital Medicine (AAP-SOHM) Listserv subscribers.

METHODS: We conducted a cross-sectional survey of subscribers of the AAP-SOHM Listserv using the survey instrument SurveyMonkey®. Our survey was coadministered with a survey on pediatric hospitalist career satisfaction.

RESULTS: The most significant barriers to delivering care to CMC were (1) time constraints (89%), (2) inadequate postdischarge resources (75%), and (3) lack of evidence-based guidelines (64%). Although most pediatric hospitalists in an inpatient service currently care for both CMC and non-CMC patients (91%), only 25% perceive this to be the optimal service model for CMC. The majority of hospitalists (56%) believe that CMC are better served by either an inpatient service dedicated to CMC (30%) or comanaged with an inpatient consult service for CMC (26%).

CONCLUSIONS: Identifying the perceived barriers to delivering care to CMC can assist pediatric hospitalists to design studies determining if care delivery is affected by these barriers. Most hospitalists care for CMC on the same service as uncomplicated patients, yet over half perceive that a different model of care delivery would better serve the needs of CMC.

Introduction

The number of children with medical complexity (CMC) has been rising as the survival rates of previously fatal conditions have improved. Two recent studies suggested that over the last decade, hospitalization rates and inpatient resource utilization for CMC have increased.

In the outpatient setting, there is ample literature that suggests that children with special health care needs benefit from the medical home model and that meticulous care coordination improves outcomes in CMC such as fewer hospitalizations, lower costs, fewer emergency department visits, and improved parent satisfaction. There is a paucity of literature regarding the optimal model of care for the hospitalized CMC, barriers to delivering care to CMC, or pediatric hospitalists’ perspectives on the best way to deliver care to these patients. Srivastava et al clearly describe that the care for hospitalized CMC should be family-centered, coordinated, aimed at minimizing harm, and focused on issues affecting the “whole child” such as nutrition and functional limitations. Historically,
subspecialist physicians have cared for CMC, yet more recently, their care has been managed by the pediatric hospitalist. Two studies attempted to identify a model for delivering care to the hospitalized CMC to improve outcomes. However, the findings of both studies are difficult to generalize because one represented subspecialty populations and the other focused on a primary care physician who also treated CMC in the hospital. The aims of our study are to identify pediatric hospitalists’ perceived views of (1) barriers to delivering care to CMC and (2) their preferred model of inpatient health care delivery for CMC.

**Subjects and Methods**

The Institutional Review Board at the University of Texas–Health Science Center San Antonio approved this study. We conducted a cross-sectional, incentivized survey of members of the American Academy of Pediatrics Section on Hospital Medicine (AAP-SOHM) and subscribers to the AAP-SOHM Listserv using a survey instrument (Survey Monkey®, Survey Monkey, Palo Alto, CA). Not all members of the AAP-SOHM subscribe to the Listserv, and not all Listserv subscribers are members of the AAP-SOHM. Pediatric hospitalists comprise most of the membership of the AAP-SOHM. Our survey instrument was coadministered with a survey on pediatric hospitalist career satisfaction to reduce the number of surveys delivered to the members.

We designed a survey to assess pediatric hospitalists’ perception in two categories: (1) barriers to delivering care to CMC, and (2) the preferred model to deliver care to CMCs. Eleven barriers to healthcare delivery were identified based on barriers previously cited in the literature and the authors’ own experiences at three different institutions. The pilot survey was administered to six experienced pediatric hospitalists to collect feedback regarding clarity of the questions and content validity. After additional input from the pilot survey, five more questions were added to construct the final 16 questions. The survey was then refined by an educational design specialist for duplication of content, leading bias, and lack of clarity (Appendix). Models of care included (1) a general pediatrics service that cares for complex and uncomplicated patients, (2) an inpatient service only for medically complex patients and (3) an inpatient consultation service specifically for medically complex patients which will assist the primary team.

Most of the survey questions were formatted in a 5-point Likert scale. A spreadsheet (Microsoft Excel®, Microsoft Corporation, Redmond, WA) was used to calculate descriptive statistics. We calculated 95% confidence intervals for proportion using the sample size and percentage of respondents for each question. Pearson chi-square and Fisher exact tests were used to compare categorical variables and a logistic model was created to examine the factors that contributed to a preference of certain clinical models of care delivery for CMC. A statistical software program (R 2.11.0, R-Foundation, Vienna, Austria) was used to perform all statistical analyses. $P<.05$ was considered statistically significant.

**Results**

We received 222 responses. AAP-SOHM and the Listserv had approximately 1,000 members at the time the survey was conducted. We estimate that the response rate was 20%. Estimating the denominator of the response rate was limited because not all AAP-SOHM members belong to the Listserv, some members have duplicate email addresses for the Listserv, and email addresses may be inactive or infrequently accessed. The Listserv also has nonhospitalist members. Table 1 shows the demographic variables of respondents. Most were women and held an academic appointment. According to AAP-SOHM personnel (S. Niccole Alexander, MPP, Manager, Division of Hospital and Surgical Services, Department of Community and Specialty Pediatrics, American Academy of Pediatrics, personal communication), 54% of the members were women.

Table 2 summarizes the respondents’ perceived barriers to delivering care to CMC. The most common barriers involved time constraints, lack of support outside the hospital setting, and absence of evidence-based guidelines to care for CMC.

Table 3 compares the types of care delivery models staffed by the respondents and the type of care delivery model they perceive would best serve CMC.

**TABLE 1** Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>% of Respondents</th>
<th>95% Confidence Intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>70</td>
<td>±6.03</td>
</tr>
<tr>
<td>Holds academic appointment</td>
<td>75</td>
<td>±5.7</td>
</tr>
<tr>
<td>Completed a fellowship program</td>
<td>13</td>
<td>±4.42</td>
</tr>
<tr>
<td>≤5 years as a hospitalist</td>
<td>63</td>
<td>±6.35</td>
</tr>
<tr>
<td>&gt;10 years as a hospitalist</td>
<td>14</td>
<td>±4.56</td>
</tr>
<tr>
<td>Practicing in a free-standing children’s hospital</td>
<td>33</td>
<td>±6.19</td>
</tr>
</tbody>
</table>
There was no statistically significant difference among the respondents’ perception of the best model of care delivery for CMC when adjusted for the actual model of service they practice.

Discussion

Our study shows that pediatric hospitalists perceive multiple barriers to caring for CMC in the inpatient setting. Pediatric hospitalists who care for CMC in the inpatient setting cite issues regarding time constraints, lack of community resources on discharge, and lack of evidence-based guidelines as the most notable barriers. Institutions that wish to provide excellent quality of care for these patients can use this information to investigate the effect these barriers have on patient outcomes and design models of care that mitigate these challenges.

The two most highly cited barriers to caring for CMC involved the lack of time and the time-intensive families of CMC. In the inpatient setting, this may be because the care coordination involves the highly rigorous tasks of not only managing medical issues, but also (1) coordinating and organizing care from subspecialists to avoid duplication of services, (2) sharing information between families and other members of the health care team, (3) care planning with particular attention to minimizing errors, (4) discharge planning including ensuring safety and accessibility for technology-dependent patients, and (5) educating families. A possible solution to address time-intensive care coordination needs for CMC include the formation of multidisciplinary teams that conduct family-centered rounds to allow all involved in the care of the complex child, including family, medical staff, and bedside nurses to be included in the decision-making.

Families are the pediatric patient’s main source of support, and offer the health care team valuable information unique to their child which helps in decision-making. Through meticulous family-centered care coordination, the hospitalist may be able to spend more time at the bedside with the families and patients to make appropriate medical decisions regarding the care of the child. Comprehensive case management support can also address the time needed to properly care for CMCs in the hospital setting. For example, the Pediatric Alliance for Coordinated Care has designated a pediatric nurse practitioner to act as a case manager for CMC in the outpatient setting, with “indications of improved health.” Although there is no literature, to our knowledge, on the use of physician extenders in the care of CMC in the hospital setting, designating a health professional specifically to coordinate care could save much of the physicians’ time so that more time is spent at the bedside with the patients and their families.

To address the perception of lack of support outside the hospital setting including inadequate postdischarge resources, lack of rehabilitation services, subspecialty support, institutional...
support, ancillary services and lack of engagement from the primary care provider (PCP), pediatric hospitalists can form partnerships with community resources and PCPs to improve the transition of CMCs from the inpatient to outpatient setting. Some of these barriers would require a change not only in culture (institutional support), but also in available resources and infrastructure (rehabilitation services). Both top-down and grass roots efforts may address these barriers to provide the necessary resources to care for CMC. Seamless transitions are imperative for these patients, because their level of complexity places them at risk for errors in care. \(^{13}\) Recent literature has addressed the importance of transitions in fragile populations; one study reported that elderly, frail patients are twice as likely to report problems after discharge when their PCP was not aware of the hospitalization\(^{22}\) and another showed that patients without “timely” PCP follow-up were more likely to be readmitted.\(^{23}\) More than half of the pediatric hospitalists who responded perceived the lack of PCP engagement in the care of CMC to be an important barrier. Conversely, a study on various physicians’ attitudes regarding pediatric hospitalists showed that more than half of the responding PCPs believed the hospitalist model would impair communication with the PCP, and two-thirds believed that the PCP was the best physician to provide inpatient care, even though most were less comfortable with inpatient care than outpatient care.\(^{24}\) Communication with the patients’ PCPs is essential to a safe, seamless transition of the CMC between inpatient and outpatient settings and serves as a way to engage the PCP.

Another important barrier noted by the respondents included the lack of evidence-based guidelines for CMCs. Although experts agree that the CMC population is important and needs special attention, evidence regarding appropriate management strategies is scarce, in large part because of the heterogeneity of the CMC population. The diversity of the group as a whole leads to small sample sizes and results that are rarely generalizable\(^{13}\) into evidence-based guidelines. If centers that care for CMC could collaborate in research trials they may be able to determine the best ways to care for these patients. Srivastava and colleagues\(^{23}\) summarized the common themes in the care of the hospitalized CMC including nutritional needs, functional limitations, multidisciplinary coordination, enterostomy tubes, tracheostomy and other airway devices, central lines, and the presence of cerebrospinal fluid shunts. These themes may need to be further explored to construct evidence-based management guidelines that can standardize and hopefully improve the care of hospitalized CMC.

The remaining barriers perceived by pediatric hospitalists which were addressed in the survey, such as the patient's level of disability, the stakeholders’ sense of futility, and the physician's comfort level and residency training may be addressed with education at the graduate medical education and the faculty development levels. Although a discussion as to the ways this could be done is beyond the scope of this study, we believe exploring these barriers in a future study would be important to develop sustainable inpatient programs that care for CMC.

To our knowledge, this is the first study addressing pediatric hospitalists’ opinions on the best way to deliver care to CMC. Our survey found that the majority of pediatric hospitalists perceive that CMC are best cared for by an inpatient service dedicated to CMC or a consultation team that can assist the primary team. However, most respondents (91%) actually take care of CMC in models where CMC and non-CMC patients are on the same service. Only 10% of respondents staff an inpatient service dedicated to CMC. There was no difference among respondents in the type of model they perceived as the best to care for CMC when adjusted for the actual model used by the respondents. The reasons for the discrepancy between actual practice and the respondents’ perceptions as to the preferred inpatient health care delivery model are unclear. The paucity of institutions with a dedicated inpatient CMC service may be related to the barriers discussed earlier, including financial constraints and lack of personnel. It stands to reason that a dedicated CMC service may positively affect the time-constraint barrier perceived by hospitalists by allowing pooling of resources such as case management support and communication with subspecialists. However, in our survey, these questions were independent of each other, therefore we cannot make inferences regarding their relationship or whether the hospitalists perceived that the time constraint barrier would be addressed specifically by a dedicated CMC service. Further study is necessary to determine the relationship between these two important variables.

While the outpatient medical home model has been evaluated in the literature, very few studies have addressed the best ways to deliver care to CMC in the hospital setting. Bekmezian and colleagues\(^{25}\) reported that their staff-only pediatric hospitalists care...
of Gastroenterology or Hematology-Oncology patients resulted in decreased length of stay and cost. Their study focused on two populations that are relatively homogeneous and may not be applicable to settings in which residents participate in the care of CMC. Berman et al16 demonstrated a shorter length of stay in children with special health care needs who were enrolled in a hospital-based comprehensive primary care clinic where the clinic physician cared for those patients when they were hospitalized and did not require intensive care. This model would likely provide the most seamless transitions in and out of the hospital for CMC, yet the current trend is for hospitalists to take care of both CMC and non-CMC patients who are admitted.

Our study has several limitations. First, the survey was sent to a Listserv made up of primarily pediatric hospitalists and we are unsure how representative the sample is of the pediatric hospitalist community across the country because 75% of respondents held an academic appointment (a similar demographic finding in a recent Pediatric Research in Inpatient Settings study survey19). Second, the response rate was low (approximately 20%) and we cannot determine how many people actually received the survey. Third, the list of barriers was not exhaustive. There may be important barriers that were not included in the survey. Finally, the survey was sent by email to the SOHM and Listserv membership, and the survey instrument was coadministered with a survey on pediatric hospitalist career satisfaction. The presence of two surveys may have affected the response rate. For example, not all respondents answered the demographic questions. Although the reasons for this are not clear, it could have been a sign of fatigue in a long series of questions. Also, the difference between the percentage of female members of AAP-SOHM (54%) and our respondents (70%) may also indicate an element of self-selection bias, though the relationship of gender with this specific topic is unclear.

We also realize many of the survey questions were subject to interpretation by the respondents. For example, the questions regarding different stakeholders’ “sense of futility” was meant to address whether respondents perceived their own, other physicians’, or families’ sense of futility as a barrier to providing care for a child whose chronic conditions would not improve. The responses appear to indicate that most hospitalists were more concerned with other physicians’ sense of futility in caring for CMC, not their own or the families’ sense of futility. By “your comfort level with medically complicated patients” we meant to ask physicians how comfortable they felt when providing care to CMC specifically and by “your training during residency” we referred to the amount of training in the care of CMC that the respondent received during residency. These questions require a measure of self-assessment that may be fraught with bias and inaccuracy. The survey design did not offer explanation for the questions (Appendix). The respondents also could have interpreted the meaning of these questions differently, which could have affected and biased the survey results as well as response rate.

Conclusions
The most common perceived barriers to delivering care to CMC include time-constraints, inadequate support outside the hospital setting, and lack of evidence-based guidelines. Determining if the perceived barriers interfere with care delivery to CMC requires further investigation. Most hospitalists care for CMC on the same service as uncomplicated patients yet over half perceive that a different model of care delivery would better serve the needs of CMC. We suggest further study comparing models for clinically important outcomes for CMC.

The authors would like to acknowledge Debra Stark, DPh, for expert assistance with survey design.

References
9. Gupta VB, O’Connor KG, Quezada-Gomez C. Care coordination services in
Appendix: Survey

Demographics:

What is your gender? Male/Female

In what year did you complete your residency? _____________________________

Did you complete a fellowship? Y/N

If yes, in what discipline? _____________________________

How many years have you worked as a hospitalist? _____________________________

Please indicate your current practice setting:

____ Free-standing academic children’s hospital
____ Academic children’s hospital or ward within an adult hospital
____ Children’s hospital or ward within a community hospital

____ Other (please specify): _____________________________

Please check all that apply:

____ I hold an academic appointment
____ I am responsible for teaching medical students
____ I am responsible for teaching residents

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Do you work:
   ___ Primarily day shifts
   ___ Primarily night shifts
   ___ A combination of days and nights

What is the average daily number of patients for whom you are directly responsible as the attending of record? (Check one):
   ___ <5 patients
   ___ 6-9 patients
   ___ 10-14 patients
   ___ 15-20 patients
   ___ >20 patients

Please estimate the percentage of clinical documentation (ie, admission H&Ps, progress notes, consult notes, discharge summaries, etc) that is currently done in an electronic health record at your primary hospital:
   ___ 0-20%
   ___ 21%-40%
   ___ 41%-60%
   ___ 61%-80%
   ___ 81%-100%

What percentage of your patients are medically complex?
   ___ 0-20%
   ___ 21%-40%
   ___ 41%-60%
   ___ 61%-80%
   ___ 81%-100%

Complex Care Survey Questions

1. Which type of service model do you think best serves the medically complex patient in the inpatient setting?
   ◦ A general pediatrics service that cares for complex and uncomplicated patients.
   ◦ An inpatient service only for medically complex patients.
   ◦ An inpatient consultation service specifically for medically complex patients that will assist the primary team.
   ◦ Not sure.
   ◦ Other (please specify)—drop down free text box here

2. Which of the following best describes the disposition of medically complex inpatients at your primary hospital?
   ◦ Most medically complex patients receive comprehensive inpatient care at our hospital.
   ◦ Medically complex patients are occasionally transferred to another institution for comprehensive inpatient care.
   ◦ Medically complex patients are usually transferred to another hospital for comprehensive inpatient care.

Skip logic: if the respondent answers that they usually transfer complex patients out to another institution, they will skip the remainder of this survey
3. Do you think the items listed below are significant barriers to providing care to medically complex patients?

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>No opinion</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of disability of patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time-intensive families</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Families’ sense of futility of care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your sense of futility of care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other physicians’ sense of futility of care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of evidence for basis of care</td>
<td></td>
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<tr>
<td>The primary care provider is not engaged in the patient’s care</td>
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<tr>
<td>Lack of subspecialty support</td>
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<tr>
<td>Lack of rehabilitation facilities or expertise</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Lack of ancillary support (physical, speech therapy, etc)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate reimbursement</td>
<td></td>
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<tr>
<td>Lack of institutional support</td>
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<tr>
<td>Inadequate community resources to support the child’s care post-discharge</td>
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</tr>
<tr>
<td>Your comfort level with medically complicated patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your training received during residency</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

4. Indicate your level of involvement for each of the following models of services for medically complex pediatric patients at your primary hospital.

<table>
<thead>
<tr>
<th>I staff this service</th>
<th>I cross cover this service</th>
<th>I am not involved with this service</th>
<th>This service does not exist at my hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>An inpatient service only for medically complex patients</td>
<td>An inpatient consultation service for medically complex patients</td>
<td>An inpatient service that cares for both medically complex and uncomplicated patients</td>
<td>An outpatient primary care practice specifically for medically complex patients</td>
</tr>
<tr>
<td>An outpatient consultation service that assists primary care providers in the care of medically complex patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. How would you rate the quality of care delivered to medically complicated patients at your primary hospital.

a. Poor
b. Marginal
c. Neutral
d. Good
e. Excellent
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