

# Preventing Hospitalizations in Children With Medical Complexity: A Systematic Review

## abstract



**BACKGROUND AND OBJECTIVES:** Children with medical complexity (CMC) account for disproportionately high hospital use, and it is unknown if hospitalizations may be prevented. Our objective was to summarize evidence from (1) studies characterizing potentially preventable hospitalizations in CMC and (2) interventions aiming to reduce such hospitalizations.

**METHODS:** Our data sources include Medline, Cochrane Central Register of Controlled Trials, Web of Science, and Cumulative Index to Nursing and Allied Health Literature databases from their originations, and hand search of article bibliographies. Observational studies ( $n = 13$ ) characterized potentially preventable hospitalizations, and experimental studies ( $n = 4$ ) evaluated the efficacy of interventions to reduce them. Data were extracted on patient and family characteristics, medical complexity and preventable hospitalization indicators, hospitalization rates, costs, and days. Results of interventions were summarized by their effect on changes in hospital use.

**RESULTS:** Preventable hospitalizations were measured in 3 ways: ambulatory care sensitive conditions, readmissions, or investigator-defined criteria. Postsurgical patients, those with neurologic disorders, and those with medical devices had higher preventable hospitalization rates, as did those with public insurance and nonwhite race/ethnicity. Passive smoke exposure, nonadherence to medications, and lack of follow-up after discharge were additional risks. Hospitalizations for ambulatory care sensitive conditions were less common in more complex patients. Patients receiving home visits, care coordination, chronic care-management, and continuity across settings had fewer preventable hospitalizations.

**CONCLUSIONS:** There were a limited number of published studies. Measures for CMC and preventable hospitalizations were heterogeneous. Risk of bias was moderate due primarily to limited controlled experimental designs. Reductions in hospital use among CMC might be possible. Strategies should target primary drivers of preventable hospitalizations. *Pediatrics* 2014;134:e1628–e1647

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### KEY WORDS

medical complexity, chronic illness/conditions, hospitalization, readmission

### ABBREVIATIONS

ACSC—ambulatory care sensitive condition  
AOR—adjusted odds ratio  
CCC—complex chronic condition  
CI—confidence interval  
CMC—children with medical complexity  
CRG—clinical risk group  
CSHCN—Children With Special Health Care Needs  
ED—emergency department  
ICD-9—*International Classification of Diseases, Ninth Revision*  
MAC—Maryland Access to Care  
MeSH—Medical Subject Headings  
MHI—Medical Home Index  
PACC—Pediatric Alliance for Coordinated Care  
PCP—primary care provider  
RN—registered nurse

Dr Collier conceptualized and designed the study, conducted primary data analysis, and drafted the initial manuscript; Dr Nelson assisted with data collection and analysis (resolved disagreements between primary reviewers) and reviewed and revised the manuscript; Dr Sklansky assisted with risk of bias data collection and analysis and reviewed the manuscript; Ms Saenz coordinated and supervised data collection, assisted with data analysis, and critically reviewed the manuscript; Drs Klitzner and Lerner assisted with project conceptualization and reviewed and revised the manuscript; Dr Chung contributed significantly to conceptualization, methodological supervision, technical oversight, and critically reviewed and edited earlier drafts; and all authors approved the final manuscript as submitted.

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Improvements in pediatric care have led to a substantial increase in the number of children surviving previously fatal complex conditions.<sup>1–4</sup> The subsequent disability, vulnerability, and dependence on technology of these children can lead to significant family and health system consequences requiring intensive care coordination to achieve optimal outcomes.<sup>4,5</sup> Nationally representative hospital samples have demonstrated that children with medical complexity (CMC) can be a small percentage of the population yet account for disproportionately high hospital utilization, including admissions, hospital days, and hospital charges.<sup>6–8</sup> Though CMC represent ~1% of the population, they may account for up to one-third of child health expenditures, with up to 80% of their cost due to inpatient care.<sup>9–10</sup> At present, no consensus exists regarding how to define or reduce potentially avoidable hospitalizations in CMC. Preliminary studies contend that utilization might be reduced through certain care coordination activities,<sup>4,11–13</sup> and some have used the patient-centered primary care medical home as a framework.<sup>14,15</sup>

Models commonly used to identify potentially preventable hospitalizations (eg, ambulatory care sensitive conditions [ACSCs]) may not apply to this particular population. For example, although gastroenteritis and dehydration may represent preventable hospitalizations in the general population, this may not be an appropriate designation in the child with a multiorgan system chronic illness, inability to tolerate enteral feedings, or a metabolic disorder. To understand and ultimately decrease hospitalizations in the complex population, drivers of preventable hospitalizations need to be identified. Interventions based on potentially modifiable drivers might lead to lower hospital utilization.

Because to our knowledge no review of preventable hospitalizations in CMC has been conducted, this systematic review

aims to examine (1) studies characterizing potentially preventable hospitalizations in CMC, and (2) interventions aiming to reduce potentially preventable hospitalizations in these children. Such a review is critical to developing evidence-based strategies most likely to succeed in reducing unnecessary hospitalizations in this high-utilizing group of patients.

## METHODS

### Data Sources and Article Selection

We searched for peer-reviewed English-language articles using Medline, Cochrane Central Register of Controlled Trials, Web of Science, and Cumulative Index to Nursing and Allied Health Literature databases from their originations, initially through May 30, 2013. The search strategy was developed with a biomedical librarian and carried out by using the AND operator to link combinations of key words and Medical Subject Headings (MeSH) terms from 3 groups of concepts: (1) children, (2) preventable hospitalization, and (3) chronic or complex illness. Additional articles were included after hand-searching the bibliographies of included articles. The comprehensive search strategy and database results are included (Supplemental Information 1). We updated the literature search to identify any new studies published through June 23, 2014.

Two reviewers (Dr Collier and Ms Saenz) used a structured screening protocol (Supplemental Information 2), refined after piloting on 5 representative articles, to independently screen titles, then abstracts, and finally full text articles. We identified studies focusing on pediatric patients with medical complexity that either characterized potentially preventable hospitalizations or tested interventions to reduce them. Using the conceptual frameworks for CMCs described by van der Lee and Cohen,<sup>4,16</sup> we only included articles in which data from CMC were available to be analyzed. A third reviewer (Dr Nelson) resolved

inclusion/exclusion disagreement between the primary reviewers.

Several specific exclusion criteria were defined before article screening. Studies exclusively looking at mental health diagnoses were excluded due to being outside the scope of the study aim. Because the organization and financing of the US health care system are sufficiently distinct from other industrialized countries, we only included studies occurring in the United States. We also excluded studies examining vaccine effectiveness or cost-effectiveness, unless they specifically examined activities to increase vaccination rates in CMC. The following study designs were excluded: case studies, letters to the editor, notes, clinical overviews, guidelines, and reviews or meta-analyses. Bibliographies of reviews were hand-searched to identify additional articles.

### Data Extraction and Synthesis

A structured data collection tool was used to extract relevant data on study design, methods, study indicators for medical complexity and preventable hospitalization, outcomes, and findings. Data pertaining to hospitalization rates, hospital days, and/or hospital costs according to the study definition for preventable hospitalization were sought. Principal summary measures included odds ratios and differences in means or proportions. Results of studies were organized according to common themes of study focus. It was also noted if the study intervention, exposures, or findings were related to medical home principles as defined by the American Academy of Pediatrics. Finally, modifiable drivers of preventable hospitalization across studies were summarized.

Risk of bias was determined by 2 independent reviewers (Drs Collier and Sklansky) using a structured data collection tool. Observational study bias was assessed by using the Agency for Healthcare Research and Quality RTI Item

Bank to Assess Risk of Bias and Confounding,<sup>17</sup> and experimental study bias was assessed by using the Downs and Black checklist for assessing methodological quality of randomized and non-randomized health care interventions.<sup>18</sup> The Downs and Black checklist power assessment was modified from a 0 to 5 to a 0 to 1 scale, where the item was scored “1” if a power calculation or sample size calculation was present and “0” if there was no power/sample size calculation or an explanation of the appropriateness of the number of subjects. The wide variability in study designs, populations, and outcomes precluded pooling of data for meta-analysis.

## RESULTS

The initial search yielded 484 titles after removing duplicates (Fig 1). After title screening, 237 titles remained for abstract screening. Of these abstracts, 195 did not meet our predefined article inclusion criteria, leaving 42 articles for full-text review. After full-text review, an additional 32 articles were excluded, leaving 10 articles for data extraction and bibliography review. Hand-search of the bibliographies from final articles produced an additional 7 articles, resulting in a total of 17 articles included in this systematic review (Tables 1, 2, and 3).

## Definitions

### *Medical Complexity*

CMC were defined heterogeneously, broadly divided into either categorical diagnosis-based schema or noncategorical consequences-based schema. Categorical systems for identifying CMCs through groups of *International Classification of Diseases, Ninth Revision* (ICD-9) diagnostic codes representing particularly complex patient populations were used in 12 studies. Five studies used complex chronic conditions (CCCs) and 1 used clinical risk groups (CRGs); both of which are well-described approaches.<sup>19–21</sup> Six other studies identified patients by

using single diagnoses or specific groups of ICD-9 codes created by the investigators for the purposes of their study. Several studies defined CMCs by using a noncategorical, consequences-based approach, eg functional limitations on the Children With Special Health Care Needs (CSHCN) screener ( $n = 1$ ), combinations of characteristics such as intensity of subspecialty use, organ system involvement, and past utilization ( $n = 2$ ), or technology assistance ( $n = 5$ ). Noncategorical approaches may capture a more diverse or inclusive cohort of children.<sup>4,21,22</sup>

### *Preventable Hospitalization*

Potentially preventable hospitalizations were defined in 1 of 3 ways: ACSCs ( $n = 5$ ), readmissions ( $n = 8$ ), or investigator-defined criteria such as after chart review or observing changes in hospitalization rates after an intervention ( $n = 7$ ).

Each of these definitions has important considerations when interpreting findings. Results from several studies suggest that ACSCs may not be ideal markers of potentially preventable hospitalization in this population. First, ACSC hospitalizations may be significantly less common in CMC. Hospitalizations for ACSCs were less common for more complex patients in 2 separate national samples.<sup>23,24</sup> Second, when ACSCs do occur among CMC, it is not clear that ambulatory care can prevent hospitalization. In the Maryland Access to Care (MAC) Medicaid experiment, investigators were only able to classify 38% of ACSC hospitalizations as avoidable.<sup>25</sup> Armour et al<sup>26</sup> found that among 81 patients with spina bifida and a hospitalization for a urinary tract infection (an ACSC), 73 had an ambulatory claim in the 7 days before hospitalization, with 47% of them receiving a diagnosis of urinary tract infections at that time. The study raises the question of how truly “ambulatory care sensitive” urinary tract infections were in this population when >90% of the patients received

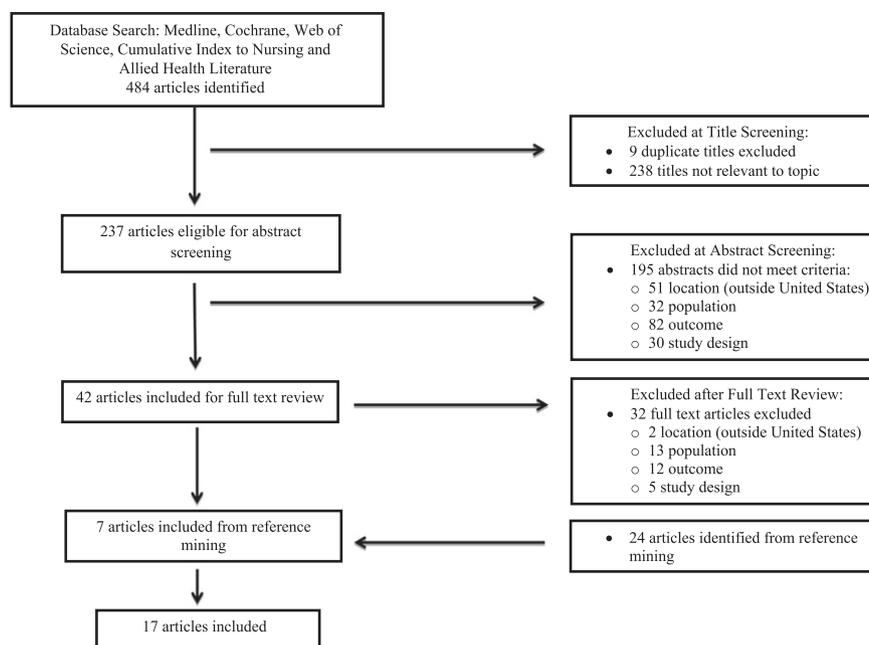
ambulatory care in the week before hospitalization.

Readmissions, assumed to frequently represent failures in care at 1 or more level, have important considerations as an indicator of preventable hospitalizations largely because there is no valid standard upon which a readmission can be labeled “preventable.”<sup>27–29</sup> Hain et al<sup>28</sup> devised a detailed 5-point Likert scale to rate preventability, which was independently applied by 4 physicians to chart reviews of 15-day readmission cases. They found that 20% of 15-day readmissions at their institution were potentially preventable, though overall agreement was difficult to achieve (and was specifically difficult in cases that were not clearly unpreventable). Finally, defining preventable hospitalizations from investigator-designed criteria are usually developed without confirming reliability and validity, making interpretation of results challenging. These definitions are also unique and therefore difficult to compare across studies.

## Clinical Antecedents to Potentially Preventable Hospitalizations

### *Medical Technology, Device Complications*

Technology assistance and complications are characteristics frequently associated with potentially preventable hospitalizations. In a nationally representative hospital discharge sample analyzing 365-day rehospitalizations, Berry et al<sup>23</sup> found that only 5% of patients with no rehospitalizations had technology assistance compared with 53% who had  $\geq 4$  rehospitalizations ( $P < .001$ ). Within this highest-utilizing group (ie,  $\geq 4$  rehospitalizations), technology complications were present in 8.7% of all admissions. Kun et al<sup>30</sup> found that tracheostomy decannulation or obstruction and tracheitis were in 12% and 17% of readmissions in the year after discharge with home mechanical ventilation, respectively. Device complications were present



**FIGURE 1**  
Flow diagram for article selection.

in 8% of a randomly selected sample of 15-day readmissions of children with chronic illnesses from another center.<sup>31</sup> Technology malfunctions were noted in 9% of admissions among patients participating in complex care programs affiliated with 4 children's hospitals.<sup>32</sup>

Though challenging to interpret degrees of preventability with device complications, a sizable proportion may be preventable through improvements in surgical, medical, or home care. A prospective study of 248 patients, in which preventability of unscheduled ICU admissions was designated by investigators after chart review,<sup>33</sup> revealed that 19% of admissions in the technology assisted chronic illness group were potentially preventable. Hain et al<sup>28</sup> found that central venous catheter infections or ventricular shunt malfunctions were present in 8.5% of all 15-day readmissions and 43% of those rated potentially preventable.

#### *Nonadherence to Recommended Hospital Follow-up*

Follow-up after discharge is a frequently studied readmission predictor

in adult studies; however, we found only 1 study addressing this question in our population.<sup>34</sup> Despite no difference in having follow-up appointments at the time of discharge, lack of outpatient hematology follow-up and disease severity were significantly associated with readmission among 100 patients with sickle cell disease ( $R^2 = 0.41$ ,  $P < .001$ ). Hematology follow-up occurred in 54% of the nonreadmitted group versus only 13% of the readmitted group ( $P < .001$ ).

#### *High-Risk Conditions*

Several specific diagnoses appear to be more commonly associated with potentially preventable hospitalizations. In the 15-day readmissions study by Hain et al,<sup>28</sup> readmissions after surgical hospitalizations were potentially preventable 39% of the time (significantly higher than after medical discharges [16%,  $P = .002$ ]).<sup>28</sup> National samples by Berry et al<sup>23</sup> and Feudter et al<sup>35</sup> identified neuromuscular and neurologic disorders as the most common CCCs associated with 365-day readmissions, and they were the second most common

15-day readmissions in the study by Gay et al.<sup>31</sup> Among studies including ACSCs, asthma was the most common ACSC<sup>23,24,36</sup>; however, it is not known from these studies what fraction of the patients with asthma ACSC hospitalizations were medically complex.

### **Primary Care Experience and Continuity Across the Health System Landscape**

#### *Medical Home Characteristics, Organizational Capacity*

Five studies<sup>15,25,37–39</sup> assessed various principles from the American Academy of Pediatrics (AAP) medical home model, in particular coordination, accessibility, and family-centeredness. In a broad sample of 43 primary care practices with varying levels of success achieving the medical home principles measured by Medical Home Index (MHI) score, fewer overall hospitalizations were observed in practices with higher MHI scores (specifically higher levels of organizational capacity, data management, chronic condition management, and care coordination).<sup>37</sup>

The analysis of the MAC Medicaid Program by Gadmonski et al,<sup>25</sup> which included 24/7 access to a medical home, revealed reduced avoidable hospitalizations after enrollment that approached statistical significance (adjusted odds ratio [AOR], 0.93; 95% confidence interval [CI]: 0.86–1.01). Similarly, a secondary data analysis of a national sample from the Medical Expenditure Panel Survey<sup>39</sup> revealed that lower parent reports of family-centered care and realized access were associated with more hospitalizations among those with private insurance (IRR, 3.87; 95% CI: 1.23–12.13 and 3.45; 95% CI: 1.30–9.19, respectively). These associations were not present in the publicly insured group, and parent report of timeliness of care was not associated with hospitalizations in either group.

**TABLE 1** Characteristics of Included Studies

| First Author (Year)             | Design                  | Population  | Medical Complexity  | Indicator of Preventable Hospitalization |             | Medical Home Principle | Primary Focus of Analysis |                           |                                |                      |
|---------------------------------|-------------------------|---|---|--|-------------|------------------------|---------------------------|---------------------------|--------------------------------|----------------------|
|                                 |                         |   |   | ACSC                                     | Readmission |                        | Other                     | Patient/ Family Behaviors | Patient/Family Characteristics | Health Care Provider |
| Armour (2009) <sup>26</sup>     | Retrospective cohort    | Patients with spina bifida and private employer-sponsored insurance or their dependents                             | Spina bifida  | X  | —           | —                      | —                         | X                         | —                              | —                    |
| Berry (2011) <sup>23</sup>      | Retrospective cohort    | Children hospitalized at 37 freestanding children's hospitals across the United States                              | CCC, Technology assistance  | X  | —           | —                      | —                         | X                         | —                              | —                    |
| Berry (2011) <sup>32</sup>      | Retrospective cohort    | Hospitalized patients who participate in a structured complex care program in 4 different children's hospitals      | CCC, neurologic impairment, technology assistance, high subspecialty use, organ system involvement, past utilization  | —  | X           | —                      | —                         | X                         | —                              | —                    |
| Cooley (2009) <sup>37</sup>     | Retrospective cohort    | Primary care practices in networks from 7 health plans in 5 states  | Cerebral palsy, epilepsy, autism  | —  | —           | X                      | —                         | —                         | —                              | X                    |
| Dosa (2001) <sup>35</sup>       | Prospective cohort      | Children with chronic conditions and unscheduled ICU admissions related to the condition in a rural New York region | Technology assistance   | —  | —           | X                      | —                         | X                         | —                              | —                    |
| Feudtner (2009) <sup>35</sup>   | Retrospective cohort    | Patients discharged from 38 children's hospitals across the United States   | CCC   | —  | X           | —                      | —                         | —                         | X                              | —                    |
| Frei-Jones (2009) <sup>34</sup> | Retrospective cohort    | Patients with sickle cell disease admitted to St. Louis Children's Hospital   | Sickle cell   | —  | X           | —                      | —                         | X                         | —                              | X                    |
| Gadomski (1998) <sup>25</sup>   | Prepost without control | Children with fee-for-service Medicaid in Maryland  | Selected conditions: immunodeficiency, cardiac anomalies, malignancies, chromosomal or congenital anomalies, cerebral palsy, metabolic disorders, cystic fibrosis | X  | —           | X                      | —                         | —                         | —                              | X                    |

TABLE 1 Continued

| First Author (Year)          | Design                                       | Population   | Medical Complexity   | Indicator of Preventable Hospitalization |             |       | Medical Home Principle |      |           | Primary Focus of Analysis |                                |                      |               |
|------------------------------|--|--|--|--|-------------|-------|------------------------|------|-----------|---------------------------|--------------------------------|----------------------|---------------|
|                              |  |  |  | ACSC                                     | Readmission | Other | ACSC                   | Home | Principle | Patient/ Family Behaviors | Patient/Family Characteristics | Health Care Provider | Health System |
|                              |  |  |  |  |             |       |                        |      |           |                           |                                |                      |               |
| Gay (2011) <sup>31</sup>     | Retrospective cohort                         | Patients with 15-d readmission to Children's Hospital  | CCC  | X  | —           | —     | —                      | —    | —         | X                         | —                              | —                    |               |
| Gordon (2007) <sup>36</sup>  | Prepost without control                      | Children enrolled in Special Needs Program at Medical College of Wisconsin   | Combinations of subspecialty use, organ system involvement, past utilization   | —  | —           | X     | X                      | —    | —         | —                         | X                              | —                    |               |
| Hain (2013) <sup>28</sup>    | Retrospective cohort                         | Randomly selected pairs of index admission/15-d readmission to Children's Hospital at Vanderbilt   | CRG  | —  | X           | X     | —                      | —    | —         | X                         | —                              | —                    |               |
| Kun (2012) <sup>30</sup>     | Retrospective cohort                         | Children started on home mechanical ventilation for chronic respiratory failure at Children's Hospital Los Angeles                               | Ventilator   | —  | X           | —     | —                      | —    | —         | X                         | X                              | —                    |               |
| Liptak (1998) <sup>12</sup>  | Quasi-experimental, nonequivalent comparison | Hospitalizations for selected conditions over 10 y at Children's Hospital in Rochester versus consortium of 18 tertiary academic medical centers | Selected conditions: cardiac disease, cancer, epilepsy, CNS dysfunction, rheumatologic and musculoskeletal disorders, spina bifida, cystic fibrosis, ventriculoperitoneal shunt, congenital nervous system and musculoskeletal disorders | —  | X           | —     | —                      | —    | —         | —                         | —                              | X                    |               |
| Lu (2012) <sup>24</sup>      | Cross-sectional                              | Kids Inpatient Database; national sample   | CCC  | X  | —           | —     | —                      | —    | —         | X                         | —                              | —                    |               |
| Palfrey (2004) <sup>15</sup> | Prepost without control                      | CSHCN from 6 practices enrolled in multifaceted medical home intervention  | Combinations of subspecialty use, organ system involvement, past utilization, development, technology assistance, severity, risk   | —  | —           | X     | X                      | —    | —         | —                         | X                              | —                    |               |
| Raphael (2011) <sup>39</sup> | Prospective cohort                           | CSHCN in Medical Expenditure Panel Survey (MEPS); national sample  | Functional limitations on CSHCN screener   | —  | —           | X     | X                      | —    | —         | —                         | X                              | —                    |               |
| Todd (2006) <sup>36</sup>    | Cross-sectional                              | Discharges from Colorado hospitals; Discharges in Kids Inpatient Database; national sample   | Selected conditions: neuromuscular, brain/spinal cord malformation, infantile cerebral palsy, muscular dystrophies   | X  | —           | —     | —                      | —    | —         | —                         | X                              | —                    |               |

X, indicates presence of the characteristic (preventable hospitalization indicator, medical home principle, and primary analytical focus); —, indicates absence of the characteristic.

**TABLE 2** Main Findings of Included Experimental Studies

| First Author (Year)           | Design                  | Sample Size/Population  | Intervention/Study Focus   | Medical Complexity  | Preventable Hospitalization   | Effect Direction <sup>a</sup> | Main Findings   |
|-------------------------------|-------------------------|---|--|---|---|-------------------------------|---|
| Gadomski (1998) <sup>25</sup> | Prepost without control | 128 025 children aged 0–18 with fee-for-service Medicaid in Maryland (3 y pre and 2 y post)                                   | MAC: Mandatory enrollment, fee-for-service primary care case management program including: (1) assigned PCP who authorizes ED, inpatient and specialty care, and (2) provides Early Periodic Screening, Diagnosis and Treatment Services, (3) higher reimbursement for physicians, hospital care and long-term care, (4) access to medical home 24/7, and (5) on-line eligibility verification system for providers  | Investigator-defined set of ICD-9 codes, including: renal disease, sickle cell disease, cardiac anomalies, chromosomal anomalies, congenital anomalies, mental retardation, cerebral palsy, malignancies, neoplasms, metabolic disorders, cystic fibrosis, HIV, other immune deficiencies | 1. Investigators developed list of avoidable hospitalizations from combinations of inpatient ICD-9 codes with ambulatory and/or pharmacy claims, eg, inpatient asthma ICD-9 code without antecedent pharmacy claim for steroids. List refined by modified-Delphi appropriateness method with expert panel.<br>2. ACSC | ↔                             | MAC enrollment no difference in avoidable hospitalization (OR, 0.93; 95% CI: 0.86–1.01), or ACSC hospitalization (OR, 0.98; 95% CI: 0.94–1.03) in final model, but all hospitalizations decreased. Avoidable hospitalization had ACSC in 92%, whereas ACSC hospitalizations were avoidable in 38%, unavoidable 12%, and unclassified 50%. As proxy for illness severity, SSI group avoidable hospitalization AOR, 1.73 (95% CI: 1.54–1.95), and ACSC hospitalization AOR, 2.81 (95% CI: 2.63–3.01). Preventive care visits associated with lower avoidable and ACSC hospitalizations, but primary care visits associated with higher avoidable and ACSC hospitalizations. |
| Gordon (2007) <sup>38</sup>   | Prepost without control | 227 (of 250) children enrolled in special needs program at Medical College of Wisconsin, up to 3 y data pre and 3 y data post | Special Needs Program: Unified care plan, coordination, and communication across specialty and primary care, participation and advocacy at specialty and primary care visits, school, with payers. Single point of contact, home visits, outreach to PCPs and community resources, RN case management, psychosocial support. MD available 24/7, rounding with inpatient services. Seventy percent in program have nurse case manager only; 30% have both program RN and MD | Program enrollment criteria = combinations of high levels of subspecialty use ( $\geq 5$ ), organ system involvement ( $\geq 3$ ), past utilization, technology assistance, additional disease, geographic and socioeconomic factors  | Reduction in hospitalizations after intervention  | ↓                             | Fewer hospitalizations and hospital days in the postperiod; 40% decrease in median admission rates, 17.6% decrease in median hospital days $P < .003$ , with corresponding increase outpatient services and decreases in charges/payments. Suspected key activities were partnership with family and PCP, familiarity with child's condition, close involvement during hospitalizations, and proactive ambulatory care.   |

TABLE 2 Continued

| First Author (Year)          | Design                                       | Sample Size/Population   | Intervention/Study Focus   | Medical Complexity  | Preventable Hospitalization                      | Effect Direction <sup>a</sup> | Main Findings  |
|------------------------------|--|--|--|---|--|-------------------------------|--|
| Liptak (1998) <sup>12</sup>  | Quasi-experimental, nonequivalent comparison | 10 715 hospitalizations for selected acute and chronic conditions between 1984 and 1995 for children <18 y, at Children's Hospital in Rochester; Compared chronic hospitalizations versus acute (appendicitis, bronchiolitis, fracture) locally and versus consortium of 18 US tertiary academic medical centers | Expanded funding by regional insurance company to provide ambulatory care coordination and wraparound services (RN, SW, Psychology, Occupational Therapy/Physical Therapy/Speech, Special Ed); 50% of population covered by this company   | Investigator-defined set of ICD-9 codes, including: cardiac disease, cancer, epilepsy, neurologic diseases, ventriculoperitoneal shunt, heme and sickle cell diseases, rheumatologic and musculoskeletal diseases, spina bifida, cystic fibrosis                      | Reduced hospital rates 30-d readmissions         | ↓                             | Annual hospitalizations for children with chronic conditions decreased from 2796 to 1622 between 1984 and 1995 ( $R^2 = 0.82$ , $P < .001$ ), and 1995 ( $R^2 = 0.82$ , $P < .001$ ), LOS decreased ( $R^2 = 0.85$ , $P < .001$ ). No change for acute admissions ( $R^2 = 0.08$ , $P = .45$ ). Compared with other academic centers, chronic condition readmits were lower (12.7% vs 15.0%, 95% CI: 10.4–14.0 vs 15.0%, 95% CI: 14.2–15.7). No denominator to compare hospitalization rates directly, but using appendicitis as proxy, found lower chronic condition hospitalizations versus other centers ( $P < .01$ ). |
| Palfrey (2004) <sup>15</sup> | Prepost without control                      | 150 CSHCN, recruited by PCPs for complexity from 6 voluntary pediatric practices in Boston (4 private practices and 2 neighborhood health centers). Data collected pre ( $n = 150$ ) and 2 y post ( $n = 117$ , 78%)   | PACC: Integrated system based on medical home principles: Multifaceted intervention to provide shared decision-making, partnership, and comprehensive care at community level, improve coordination/communication among PCPs, subspecialists, and families. Key activities: Nurse practitioner and home visits, consultation from local parent of CSHCN, modifications of office routines, individualized health plans, regularly scheduled continuing medical education, expedited referrals, and communication with specialists/hospital | Program enrollment criteria = combinations of high levels of subspecialty use ( $\geq 2$ ), organ system involvement ( $\geq 2$ ), high severity, past utilization, technology assistance, or significant development problems or risks, care coordination difficulty | Reduction in hospitalizations after intervention | ↓                             | Annual hospitalization rates decreased from 58% to 43.2% of patients ( $P < .01$ ). When stratified by age, there was no difference in 6–18 y olds. (The 0–5 y olds decreased from 62.9% to 45.2%). Almost 40% of families noted improvement in respite and transportation services. No change in reports of access for care, telephone advice, prescription refills, specialized equipment, and supplies. Findings between white and nonwhite children appeared to be equal.  |

<sup>a</sup> ↓, Main predictor or intervention associated with increased preventable hospitalizations; ↑, Main predictor or intervention associated with reduced preventable hospitalizations; ↔, No significant (or inconsistent) association between main predictor or intervention and preventable hospitalizations.

**TABLE 3** Main Findings of Included Observational Studies

| First Author (Year)         | Design               | Sample Size/Population  | Intervention/Study Focus  | Medical Complexity                 | Preventable Hospitalization     | Association Direction <sup>a</sup> | Major Findings  |
|-----------------------------|----------------------|---|---|------------------------------------|---------------------------------|------------------------------------|---|
| Armour (2009) <sup>26</sup> | Retrospective cohort | 4395 individuals aged 0–64 y with spina bifida and private employer-sponsored insurance (or their dependents) | Hospitalization rates and hospital expenditures due to urinary tract infections in this population versus population without spina bifida | Spina bifida                       | UTI                             | ↑                                  | Patients with spina bifida had 22.8 UTI discharges/1000 persons over 3 y compared with 0.44/1000 persons without spina bifida. Of 81 hospitalized for UTI, 73 had ambulatory claim within 7 d before hospitalization (34 diagnosed with UTI). Reduction in UTI hospitalization by 50% may reduce expenditures by \$4.4 million/1000 patients. Smaller % of hospitalizations associated with ACSCs in those with ≥4 readmissions (14% of hospitalizations versus 23.1% among those with 0 readmissions, <i>P</i> < .001). Among those with ≥4 readmissions (<3% of sample), accounted for 18.8% admissions, 23.4% bed days, and 23.2% charges. 52.6% had technology assistance (vs 5.3% with 0 readmissions, <i>P</i> < .001), technology complications noted in 8.7%, CCC in 89% (vs 22.3% with 0 readmissions, <i>P</i> < .001). Most prevalent CCCs were neuromuscular (39.6%) and cardiovascular (22.4%). Asthma, pneumonia, gastroenteritis, and seizure = most common ACSC hospitalization among patients with ≥4 readmits and account for 80% of their ACSCs. |
| Berry (2011) <sup>23</sup>  | Retrospective cohort | 317 643 children hospitalized at 1 of 37 freestanding children's hospitals across the United States           | Characterize children with recurrent 365-d readmissions to children's hospitals   | 1. CCC<br>2. Technology assistance | ACSC readmission<br>Readmission | ↓                                  |   |

TABLE 3 Continued

| First Author (Year)         | Design               | Sample Size/Population  | Intervention/Study Focus  | Medical Complexity  | Preventable Hospitalization        | Association Direction <sup>a</sup> | Major Findings  |
|-----------------------------|----------------------|---|---|---|------------------------------------|------------------------------------|---|
| Berry (2011) <sup>32</sup>  | Retrospective cohort | 1083 hospitalized patients who participated in a structured inpatient and/or outpatient complex care program in 4 different children's hospitals                                    | Hospitalization characteristics among patients receiving care coordination in complex care programs | <ol style="list-style-type: none"> <li>CCC</li> <li>Neurologic impairment</li> <li>Technology assistance</li> <li>Program enrollment criteria = different combinations of high levels of subspecialty use, organ system involvement, technology assistance, past utilization</li> </ol> | 30-d Readmissions                  | ↑                                  | <p>30 d readmit rate = 25.4% (mean 3.1 ± 2.8 admits per patient over 2 y). Highest rates among patients with technology assistance, neurologic impairment or other CCCs, compared with patients in complex care program without these characteristics and compared with nonprogram patients without these characteristics. Most common principal diagnoses for all hospitalizations were respiratory (29%, pneumonia/bronchiolitis 9.4%, asthma only 1.8%), followed by GI nutrition (15.8%; vomit and feeding difficulties at 3.4%), and followed by technology problem (9%).</p> <p>Reduced hospitalizations with higher MHI score (<math>\beta = 0.19, P &lt; .01</math>), and subcomponents: organizational capacity, chronic condition management, care coordination and data management (<math>\beta = 0.14</math> to <math>-0.2</math>) after controlling for chronic condition. Majority of sample for utilization analysis had asthma or ADHD (90.9%), &lt;6% had other diagnoses.</p> |
| Cooley (2009) <sup>37</sup> | Retrospective cohort | 43 primary care practices (of 60 identified) in networks from 7 health plans in 5 states that volunteered to participate (6 plans exclusively Medicaid, and seventh was commercial) | Hospital utilization associations with MHI scores   | Investigator selected conditions: cerebral palsy, epilepsy, autism, ADHD, asthma, diabetes  | Variation in hospitalization rates | ↓                                  |   |

**TABLE 3** Continued

| First Author (Year)           | Design               | Sample Size/Population   | Intervention/Study Focus   | Medical Complexity   | Preventable Hospitalization  | Association Direction <sup>a</sup> | Major Findings   |
|-------------------------------|----------------------|--|--|--|--|------------------------------------|--|
| Dosa (2001) <sup>35</sup>     | Prospective cohort   | 248 children under 18 y with chronic conditions and unscheduled ICU admissions related to the chronic condition admitted to the only ICU in a largely rural 17-county region in upstate New York | Relative risk of unscheduled pediatric ICU admissions in children with chronic health conditions compared with those without | 1. CSHCN, definition from Maternal and Child Health Bureau<br>2. Technology assistance | Chart review by investigators: events leading to hospitalization categorized into 1 of 6 categories, 5 of which considered potentially preventable | ↑                                  | Thirty-two percent of admissions were potentially preventable in chronic illness group. Chronic versus healthy preventable hospitalizations not reported. Among chronically ill: fewer admissions in the technology assisted group were potentially preventable: 19% vs 38% with chronic illness but no tech, $P < .05$ . Potentially preventable family and environmental factors in 18% (noncompliance, inappropriate supervision, tobacco smoke); health system deficiencies involved in 21% (inadequate care coordination, failure to provide mental health or hospice). More ICU admissions in chronic illness compared with healthy, RR, 3.3 (95% CI: 2.5–4.2), and RR, 3.73 (95% CI: 3.30–4.22) for technology assisted subgroup. 16.7% of all discharges had readmit within 1 y. CCC readmit AORs ranged from 1.2, 95% CI: 1.1–1.3 (cardiovascular) to 1.6, 95% CI: 1.5–1.7 (neurologic) excluding malignancy and compared with no CCC. Discharge with home health AOR 1.2, 95% CI: 1.1–1.3). Also higher odds with older age, African American race/ethnicity, public payer, longer LOS, high number and more recent past admissions. Model |
| Feudtner (2009) <sup>35</sup> | Retrospective cohort | 186 856 patients ages 2–18 y discharged from 1 of 38 children's hospitals across US during 2004 (Pediatric Health Information System)  | Predictors of 365-d readmission  | CCC  | 365-d readmission  | ↑                                  |  |

TABLE 3 Continued

| First Author (Year)             | Design               | Sample Size/Population  | Intervention/Study Focus   | Medical Complexity         | Preventable Hospitalization | Association Direction <sup>a</sup> | Major Findings   |
|---------------------------------|----------------------|---|--|----------------------------|-----------------------------|------------------------------------|--|
| Frei-Jones (2009) <sup>34</sup> | Retrospective cohort | 100 patients with sickle cell disease younger than 21 y admitted to St. Louis Children's Hospital over 12-mo period       | Predictors of 30-d readmission in patients with sickle cell disease. | Sickle cell                | 30-d readmission            | ↑                                  | has good positive predictive value, limited sensitivity.<br>Bivariate readmission associated with no home follow-up, OR, 7.7, 95% CI: 2.4–24.4. In multivariate model, ≥3 admits in past year and discharge follow-up were significantly associated, $P < .01$ $R^2 = 0.41$ . Fifty percent were given home follow-up appointments (53% nonreadmit, 43% readmit, $P = .8$ ), 42% went (54% nonreadmit, 13% readmit, $P < .001$ ).  |
| Gay (2011) <sup>31</sup>        | Retrospective cohort | 2546 cases, 1435 unique patients, with 15-d readmission to Children's Hospital at Vanderbilt (of 30 188 total admissions) | Characterize patients readmitted within 15-d of discharge            | CCOs plus asthma, diabetes | Unplanned 15-d readmission  | ↑                                  | Most readmits were in patients with chronic illness (78% of total). Compared with those with acute illness, chronic illness patients were median 5 y older, with median 2 d higher index and readmit LOS ( $P < .001$ ). Higher proportion of readmits in chronic illness were planned (25.5% vs 3.2%), a complication of a device (8% vs 1.2%), or related to index admission (95.3% vs 81.9%). Lower proportion of 0–7 d readmits were planned or for chronic illnesses than at 8–15 d (planned 18% vs 24.5%, $P < .001$ , chronic illnesses 75.4% vs 82%, $P < .001$ ). The 14.4% of patients with ≥3 readmits accounted for 43.7% of all |

TABLE 3 Continued

| First Author (Year)       | Design               | Sample Size/Population   | Intervention/Study Focus  | Medical Complexity   | Preventable Hospitalization   | Association Direction <sup>a</sup> | Major Findings   |
|---------------------------|----------------------|--|---|--|---|------------------------------------|--|
| Hain (2013) <sup>28</sup> | Retrospective cohort | 200 randomly selected pairs of index admission/15-d readmission to Children's Hospital at Vanderbilt                               | Preventability of 15-d readmissions   | CRGs (3M)  | Investigator-defined 5-point Likert scale independently scored by 4 pediatricians | ↔                                  | readmits. Oncology patients had highest unplanned readmits (20.7%), then neurologic conditions (9.5%). Potentially preventable readmit rate = 20%, 95% CI: 14.8–26.4. Central venous catheter infection or ventricular shunt malfunctions in 8.5%. Surgical admits more often "more likely preventable" readmission (38.9% vs 15.9%, <i>P</i> = .002). Preventability was similar for each of the CRG groups except malignancy (5% more likely preventable in malignancy versus 24.7% to 26.7% more likely preventable in other CRGs, <i>P</i> = .003). Most agreement when rating planned readmits. More than 2 of the 4 reviewers never agreed on rating "preventable in most cases." Significant chronic illness in 74% of sample. Nonelective 12-mo readmission rate = 40%, and 28% occurred in first month. Pneumonia (28%), tracheitis (17%), and tracheostomy decannulation/obstruction (11.5%) were most common readmit causes. Change in care management 7-d before discharge had bivariate association with readmit (18% vs 3%, <i>P</i> = .014). In |
| Kun (2012) <sup>30</sup>  | Retrospective cohort | 109 children ages 0–21 y started on home mechanical ventilation for chronic respiratory failure at Children's Hospital Los Angeles | Identify risk factors for nonelective 12-mo readmission in patients with newly initiated home ventilation | Chronic respiratory failure with newly initiated home mechanical ventilation | Nonelective 12-mo readmission   | ↔                                  |  |

TABLE 3 Continued

| First Author (Year)          | Design             | Sample Size/Population   | Intervention/Study Focus   | Medical Complexity   | Preventable Hospitalization   | Association Direction <sup>a</sup> | Major Findings  |
|------------------------------|--------------------|--|--|--|---|------------------------------------|---|
| Lu (2012) <sup>24</sup>      | Cross-sectional    | 1 326 650 weighted admissions ages 3 mo to 17 y from Kids Inpatient Database (KID), containing discharge data from 38 states based on sample from 3739 US community hospitals and 45 children's hospitals; national sample | Hospital days, hospital charges, and demographic characteristics of nationally representative sample of potentially preventable hospitalizations | CCOs   | ACSC as primary diagnosis; list adapted to remove adult conditions except Pelvic Inflammatory Disease and add failure to thrive, vaccine-preventable diseases | ↓                                  | <p>multivariate analysis, no statistically significant associations observed between readmission and demographic or clinical characteristics.</p> <p>Fewer ACSC admissions had CCC than non-ACSC (10.8% vs 16.1%, <math>P &lt; .001</math>).</p> <p>Children with ACSC admission less likely to have comorbid CCC (AOR, 0.64; 95% CI: 0.60–0.69).</p> <p>Asthma and pneumonia = 48.4% and 46.7% of ACSC hospital charges and days respectively. Children hospitalized with ACSC were more likely boys, nonwhite, publicly insured, or admitted through the ED. Lowest income quartile not associated.</p> |
| Raphael (2011) <sup>39</sup> | Prospective cohort | 1591 CSHCN under 18 y in Medical Expenditure Panel Survey (MEPS); national sample  | Parent-report quality of primary care (family-centered, timely, accessible) and subsequent hospitalization                                       | CSHCN Screener (MEPS does not include "at risk" component) | Different hospitalization rates across different CSHCN groups suggests some hospitalizations may be preventable   | ↑                                  | <p>Hospitalization rate = 4.3%.</p> <p>High-quality family centeredness observed 68.3% timeliness 51.5% access in 80.4%. Private insurance: Low family-centered care associated with more hospitalizations (incident rate ratio (IRR), 3.87; 95% CI: 1.23–12.13); low accessibility associated with more hospitalizations (IRR, 3.45; 95% CI: 1.30–9.19). Timeliness not associated with hospitalizations. Public insurance: no relationships with quality.</p>   |

**TABLE 3** Continued

| First Author (Year)       | Design          | Sample Size/Population  | Intervention/Study Focus  | Medical Complexity   | Preventable Hospitalization  | Association Direction <sup>a</sup> | Major Findings   |
|---------------------------|-----------------|---|---|--|--|------------------------------------|--|
| Todd (2006) <sup>36</sup> | Cross-sectional | Discharges from Colorado hospitals, ages 28 d to <18 y (2003, n = 26 931); Discharges in Kids Inpatient Database (KID), ages 28 d to <18 y (2000, n = 1 932 883), national sample | ACSC hospitalization relative rates stratified by insurance and patient characteristics | ICD-9 codes for neuromuscular, brain and spinal cord malformations, mental retardation, central nervous system disease, cerebral palsy, muscular dystrophies | ACSC modified list: asthma, diabetes, vaccine preventable disease, psychiatric disease, and appendectomy with perforated appendix or peritonitis | ↑                                  | Colorado: public/no versus private insurance had higher hospitalization rates for chronic disease (RR, 1.76; P < .001). Higher RR also observed across subgroups including ACSC hospitalizations and All Patient Refined Diagnosis Related Group severity >2. Independent associations with hospitalizations of public/no insurance and nonwhite race/ethnicity, age, chronic disease and ACSC (all P < .002). Similarly, US sample, public/no versus private insurance had higher hospitalization RR for chronic disease (2.20, 95% CI: 2.18–2.21), asthma (2.37, 95% CI: 2.34–2.40), and diabetes (1.39, 95% CI: 1.36–1.42). |

ADHD, attention-deficit/hyperactivity disorder; GI, gastrointestinal; LOS, length of stay; MEPS, Medical Expenditure Panel Survey; RR, relative risk; UTI, urinary tract infection.

<sup>a</sup> ↑, Main predictor or intervention associated with increased preventable hospitalizations; ↓, Main predictor or intervention associated with reduced preventable hospitalizations; ↔, No significant (or inconsistent) association between main predictor or intervention and preventable hospitalizations.

### Complex Care

Palfrey et al<sup>15</sup> reported the prepost evaluation results from the Pediatric Alliance for Coordinated Care (PACC) multisite pilot intervention in Massachusetts, and Gordon et al<sup>38</sup> reported prepost findings from the Special Needs Program at the Children's Hospital of Wisconsin. Both studied multifaceted, multidisciplinary interventions focused on coordination and partnership with particularly complex patients identified through eligibility criteria including combinations of subspecialty use, organ system involvement, technology assistance, developmental delays, past utilization, and future uncertainty or risk.

Key PACC activities included nurse practitioner involvement and home visits, consultation from a local parent of a CSHCN, modifications of office routines, individualized patient health plans, regularly scheduled continuing medical education, expedited referrals and communication with specialists/hospitals. Key Special Needs Program activities included unified care plans, coordination, and communication across inpatient and outpatient specialty and primary care. Additional activities included participation at health care visits, school, and with payers, home visits, outreach to primary care providers (PCPs) and community resources, registered nurse (RN) case management, psychosocial support, and physician availability 24/7. Both evaluations, though uncontrolled, revealed significant reductions in hospital utilization with relatively modest programmatic cost requirements.

### Health Services Systems and Policies

#### Organization and Payer Structure

Investigators in upstate New York conducted an evaluation after a regional insurance company expanded funding for ambulatory care coordination and wrap-around services (nursing, social work,

psychology, occupational therapy/physical therapy, speech therapy, and special education) for children with chronic diseases.<sup>12</sup> Over 10 years, hospitalizations for children with heterogeneous complex disorders reduced from 2796 to 1622 ( $R^2 = 0.82$ ,  $P < .001$ ) at their hospital, without any simultaneous change observed in common acute hospitalizations (bronchiolitis, fracture, and appendicitis). The 30-day readmission rates were lower than a comparison academic hospital group (12.7% vs 15%); and overall hospitalization rates for chronic conditions were lower using appendectomy rates as a proxy denominator for the overall hospitalization rates ( $P < .01$ ).

Another quasi-experiment, MAC,<sup>25</sup> which included PCP assignment and managed care gatekeeping for emergency department (ED), inpatient and specialty care, improved reimbursement for primary care, and 24/7 access for patients in the Medicaid program, evaluated changes in hospitalization rates, ACSC hospitalizations, and an investigator-defined indicator of “avoidable hospitalizations.” The latter group was defined by prespecified combinations of ICD-9 codes with ambulatory and/or pharmacy claims after consensus from a modified-Delphi process with local experts. MAC enrollment was associated with a lower probability of avoidable (AOR, 0.89; 95% CI: 0.83–0.97), but not ACSC hospitalization (AOR, 0.96; 95% CI: 0.92–1.01) among children who used ambulatory care. After including ambulatory visit types in the final model (subspecialty, primary care, preventive, and ED), there was a nonstatistically significant reduction in avoidable hospitalizations with enrollment (AOR, 0.93; 95% CI: 0.86–1.01). Preventive visits were significantly associated with lower avoidable and ACSC hospitalizations (AOR = 0.70 and 0.83, respectively).

## Beyond Hospital and Clinic Boundaries

### *Home Visitation and Community Resources*

Both interventions by Gordon et al<sup>58</sup> and Palfrey et al<sup>15</sup> (described earlier) included home visitation and connection to community resources as key components. Neither was controlled nor designed to identify the specific program activities accounting for outcomes, so it remains unclear if these activities, specifically, were responsible for reduced hospitalizations.

### *Environmental Exposures and Triggers*

In a study by Dosa et al,<sup>33</sup> noncompliance, inappropriate supervision, and passive smoke exposure preceded 18% of all ICU admissions designated as potentially preventable and 8% of those for the children with technology assistance. When these investigators categorized the events leading to an admission, potentially preventable family and environmental factors accounted for 43% of all events leading to an admission.

### **Demographics: Increased Vulnerability, Less Modifiability**

Public insurance,<sup>23,24,35</sup> age,<sup>23,25,31,35,36</sup> and nonwhite race/ethnicity<sup>23–25,35</sup> were consistently associated with higher potentially preventable hospitalizations when included in analyses. Despite being largely unmodifiable, recognizing the increased vulnerability these characteristics introduce is important.

Based on the results from all included studies, a summary of key drivers of potentially preventable hospitalizations are presented in Table 4.

### **Strength of the Evidence**

Most of the studies were rated as having at least medium risk of bias due to design flaws (Tables 5 and 6). Four studies used quasi-experimental designs,

none of which were randomized. Three studies were uncontrolled pretest designs, and 1 was a natural experiment with a nonequivalent comparison group. Among the observational studies, though many attempted to account for potential confounders such as demographics and severity of illness, most were missing important variables: family income and employment, family and household structure, caregiver education, caregiver or patient health literacy, self-efficacy, mental health, adherence, community characteristics and resources, as well as distance to care, among others. Because several of the studies were small pilot or single-center studies, generalizability of findings to different health care settings or patient populations is also limited.

## **DISCUSSION**

Evidence from this review suggests that hospitalizations can be reduced in CMC. Because these children account for as much as one-third of child health expenditures,<sup>8,10</sup> and because hospital care may account for 80% of spending in this group,<sup>9</sup> these findings are important. Progress in this field has the potential to lead to significant cost savings, higher care quality, and improved patient experience in a particularly vulnerable cohort. These findings lay the foundation for additional research by identifying candidate drivers, or root causes, of potentially preventable hospitalizations upon which interventions can be designed and tested.

Both home and immediate postdischarge environments appear to be high-yield focal points given their relationship to detrimental factors including adherence problems, inadequate technology use and maintenance, family stress, passive smoke and other environmental exposures, and insufficient follow-up or information transfer. Research with chronically ill adults suggests that increased patient activation (ie, the skills, knowledge, confidence and motivation to

**TABLE 4** Modifiable Drivers of Hospital Use Among CMC

| Patient and Family Drivers   | Health Care Drivers  |
|--|--|
| 1. Medical technology or device complication   | 1. Lack of practice-level capability and continuing education to perform effective care coordination, chronic condition management, data management  |
| 2. Postsurgical complication   | 2. Absence of capacity/skill to redesign office activities   |
| 3. Harmful environmental exposure, including passive smoke and inappropriate supervision of the child  | 3. Lack of parent input in clinical program design and execution   |
| 4. Nonadherence to prescribed treatments   | 4. No home visitation  |
| 5. Nonadherence to follow-up recommendations after discharge   | 5. Inadequate continuity or postdischarge follow-up  |
| 6. Neurologic disorders and possibly asthma are prevalent diagnoses among potentially preventable hospitalizations (unclear how modifiable, though awareness of their vulnerability may be relevant) | 6. Insufficient direct involvement/communication of PCP across inpatient–outpatient–subspecialty–community settings  |
| 7. Underrepresented (nonwhite) race/ethnicity or disadvantaged socio-demographics, for example, lower income or public insurance (less likely modifiable)  | 7. No individualized and unified care plan   |
|  | 8. Insufficient payer or institutional commitment of resources to coordinate care for medically complex population, including ancillary services (nursing, social work, therapy, special education and mental health services) |
|  | 9. Poor family experience with access, family-centered care, or psychosocial support   |

maintain one's health and health care) is associated with less ED and hospital use as well as fewer readmissions.<sup>40–42</sup> If these findings translate to caregivers of CMC, testing interventions designed to increase caregiver activation and improve care at home may be effective. Additionally, telehealth interventions with nurse chronic illness management have reduced ED use and preventable hospitalizations in elderly and Veterans Affairs patients,<sup>43,44</sup> and such approaches may be germane to CMC receiving care at home.

High-quality hospital-to-home transitions practices, such as the Care Transitions Intervention developed for the geriatric population, might also be adaptable to families of CMC. Controlled studies of this

intervention have revealed that combining postdischarge home visitation, self-care, and health coaching activities for patients and caregivers has led to improvements in caregiver activation and self-management with reductions in cost and readmissions in the months after discharge.<sup>45–48</sup> Promising work that builds off the community health worker model<sup>49</sup> and nurse case management programs<sup>50</sup> have also led to reduced utilization after discharge. Refining and testing optimal home visit logistics, scope, and content as well as post-discharge activities are important next steps with the CMC population.

Several additional strategies should be sought to reduce CMC hospital use. Building on the findings of Cooley et al,<sup>37</sup>

Gordon et al,<sup>38</sup> and Palfrey et al,<sup>15</sup> effective models for written and verbal communication spanning across the inpatient-outpatient-community continuum will likely lead to reductions in hospital use. A landmark review by Kripalani et al<sup>51</sup> highlighted the prevalence of deficits in communication transfer between hospital-based and primary care physicians, noting negative effects on quality of care in 25% of follow-up visits and possibly increased readmissions. Efforts to eliminate complications from medical devices and technologies, and efforts to anticipate, identify, and mitigate postsurgical complications also appear promising.

Practice-level redesign with an emphasis on chronic care management, organizational capacity, population-based management, and team-based care may also be particularly successful. Involving parents as stakeholders in these processes is necessary, and involving experts in redesign or chronic care management may be prudent for practices lacking these skills. Achieving success as a patient- and family-centered medical home may have potential for reducing hospitalizations. Finally, advocating or collaborating with payers to redesign payment structures for this population may be an effective approach at the health system level.

This review also underscores the need to better define preventable hospitalizations. Increasing numbers of studies demonstrate the challenges of interpreting readmission rates,<sup>27,52,53</sup> including poor reliability in identifying preventable readmissions.<sup>28</sup> To date,

**TABLE 5** Risk of Bias of Included Studies: Experimental Studies

| First Author (Year)           | Design <sup>a</sup>                             | Reporting<br>(Maximum 11) | External Validity<br>(Maximum 3) | Bias<br>(Maximum 7) | Confounding<br>(Maximum 6) | Power<br>(Maximum 1) |
|-------------------------------|---|---------------------------|----------------------------------|---------------------|----------------------------|----------------------|
| Gadomski (1998) <sup>25</sup> | Prepost without control                         | 8                         | 1                                | 4                   | 4                          | 0                    |
| Gordon (2007) <sup>38</sup>   | Prepost without control                         | 9                         | 1                                | 5                   | 2                          | 0                    |
| Liptak (1998) <sup>12</sup>   | Quasi-experimental,<br>nonequivalent comparison | 6                         | 2                                | 4                   | 2                          | 0                    |
| Palfrey (2004) <sup>15</sup>  | Prepost without control                         | 9                         | 1                                | 5                   | 4                          | 0                    |

<sup>a</sup> Instruments: Experimental designs = Modified Downs and Black Checklist, 18 higher scores reflect less bias.

**TABLE 6** Risk of Bias of Included Studies: Observational Studies

| First Author (Year)             | Design <sup>a</sup>  | Bias   | Confounding |
|---------------------------------|----------------------|--------|-------------|
| Armour (2009) <sup>26</sup>     | Retrospective cohort | Medium | Low         |
| Berry (2011) <sup>23</sup>      | Retrospective cohort | Low    | Low         |
| Berry (2011) <sup>32</sup>      | Retrospective cohort | Medium | High        |
| Cooley (2009) <sup>37</sup>     | Retrospective cohort | Medium | Low         |
| Dosa (2001) <sup>35</sup>       | Prospective cohort   | Medium | High        |
| Feudtner (2009) <sup>35</sup>   | Retrospective cohort | Low    | Low         |
| Frei-Jones (2009) <sup>34</sup> | Retrospective cohort | Low    | Low         |
| Gay (2011) <sup>31</sup>        | Retrospective cohort | Medium | Medium      |
| Hain (2013) <sup>28</sup>       | Retrospective cohort | High   | High        |
| Kun (2012) <sup>30</sup>        | Retrospective cohort | Low    | Low         |
| Lu (2012) <sup>24</sup>         | Cross-sectional      | Medium | Medium      |
| Raphael (2011) <sup>39</sup>    | Prospective cohort   | Low    | Low         |
| Todd (2006) <sup>36</sup>       | Cross-sectional      | Medium | Medium      |

<sup>a</sup> Instruments: Observational designs = Agency for Healthcare Research and Quality RTI Item Bank,<sup>17</sup> Bias = Q1, 3, 7, 8, 9, 11; Confounding = Q6, 12, 13. Authors defined risk as follows: low risk if no affirmative answers, medium risk if 1 affirmative response, and high risk if >1 affirmative response.

separation of preventable readmissions from all readmissions cannot be accomplished by using administrative data alone. ACSC hospitalizations may be as difficult to interpret in this population. A study reviewing physician and parent perspectives on the preventability of ACSCs in a sample of consecutively enrolled patients to a children's hospital revealed that only 13% to 46% of hospitalizations for ACSCs were thought to be avoidable,<sup>54</sup> and the authors did not look specifically at a medically complex cohort. Findings from our work suggest that ACSC hospitalizations may be less common for CMC than non-CMC.

### Limitations

A number of limitations should be considered. In addition to a relatively small number of published studies on this topic, the consistency and quality of this body of evidence is the major limitation of the review. The variability in patient

populations, indicators of preventable hospitalization, and outcome measures limits synthesis of findings. The experimental designs are uncontrolled pilot studies or quasi-experimental nonequivalent comparisons. As such, drawing conclusions about causality from any of the interventions or exposures to changes in hospital use is challenging. We only included published, peer-reviewed publications, and it is possible that unpublished interventions exist. We were unable to formally assess risk of bias across studies such as through construction of a funnel plot, due to the limited number of included studies and heterogeneity of outcomes. Publication bias may have prevented intervention evaluations with negative findings from entering peer-reviewed journals. Finally, because of CMC definition heterogeneity, it is possible that ultimately preventing hospitalizations may require different approaches depending

on the CMC population captured by the definition.

Nevertheless, while awaiting higher quality studies to be completed in the future, providers and health systems will continue to try to reduce hospital utilization in this population; and as such, developing strategies from the existing evidence is pragmatic. Given the relatively small number of published studies to date, intervention development might be aided by augmenting these findings with expert panel approaches such as the modified-Delphi Rand/UCLA Appropriateness Method.<sup>55</sup>

### CONCLUSIONS

The call to reduce health care costs combined with the reality that expenditures and hospital use are disproportionately high among CMC means that reducing hospital utilization in this population is an important target for every health system. Research progress is challenged by relatively small patient numbers and heterogeneous diagnoses within single centers. Innovation and testing of new models that are informed by this study can be accomplished today, however, through opportunities offered by primary care research networks, quality improvement collaboratives, and partnership among the increasing number of complex care programs.<sup>9,32</sup> This systematic review of the literature has identified several modifiable drivers of preventable hospitalization in CMC. Efforts targeting these factors specifically may lead to reductions in hospital use in this medically complex population.

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## Preventing Hospitalizations in Children With Medical Complexity: A Systematic Review

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