


A scoping review to inform care coordination strategies for youth with traumatic brain injuries: Care coordination tools

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Abstract

Introduction & importance: Children with traumatic brain injury (TBI) report unmet needs several years after their injury and may require long-term care. However, this chronic health condition is often only treated and monitored in the short-term. Care for young persons with TBI often relies on parents to manage their child's complex care network. Effective care coordination can close these gaps and facilitate continuity of care for children with TBI. The purpose of this scoping review was to develop a better understanding of tools that improve care coordination for Children with Special Health Care Needs (CSHCN). This, in turn, can inform care for children with TBI.

Methods: A scoping review was conducted following the PRISMA framework and methodology. OVID/Medline, CINAHL, PsycINFO, EMBASE, and ERIC databases were searched for articles relevant to care coordination tools used with CSHCN.

Results: 21 articles met the criteria for inclusion in the review, and 6 major categories of care coordination tools were identified: telehealth, online health records and tools, care plans, inpatient discharge protocols, family training, and reminders.

Discussion: Studies examining telehealth, online tools, care plans, and family training care coordination interventions for CSHCN have shown positive outcomes and would be relevant strategies to improve the care of children with TBI. Future prospective research should investigate these tools to explore whether they might improve communication, reduce unmet needs, increase service access, and improve long-term outcomes for children with TBI.

Keywords

Coordination, complex intervention, clinical pathways

Introduction

Traumatic brain injury (TBI) is a substantial public health burden internationally. The global incidence of TBI is estimated to be 69 million individuals each year,¹ and TBI is the leading trauma-related cause of death and disability.² Children are among the groups most likely to experience TBI, with an incidence rate of 47 to 280 per 100,000 children worldwide.³ TBI poses a significant risk to youth, as it suddenly disrupts a child's development and can result in significant long-term issues that negatively impact behavior, health, academic success, employment opportunities, and quality of life.^{4–9} To address the interplay of these long-term symptoms and issues that require the care of a variety of professionals, children with TBI need systematic care coordination. Although the definitions used for care coordination are often heterogeneous, care coordination is

broadly defined as “the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the

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appropriate delivery of health care services".¹⁰ However, in a survey of 23 European countries, it was found that there are limited mechanisms in place between systems of care to support care coordination for children with TBI.¹¹ These same gaps in care are noted in the United States.¹² Although care coordination should be a key element in caring for youth with TBI, more guidance is needed on how to best implement policies and procedures for care coordination in this complex population.

Immediate and long-term care are vital to optimize children's outcomes after a TBI. Yet, children often report unmet or unrecognized needs many years after injury.¹³⁻¹⁵ There are significant variations in discharge recommendations and referrals following acute care hospitalization with the majority of children being discharged home, rather than to inpatient rehabilitation facilities where more favorable long-term outcomes can be achieved.¹⁶ Without the support of inpatient rehabilitation, parents must independently organize and manage their children's care, and children are less likely to be referred for outpatient rehabilitation services.¹⁷ Children with TBI have needs that may change over time¹⁸ and require the care of a variety of specialists (e.g. physiatrists, neurosurgeons, occupational, physical, or speech therapists), necessitating a well-coordinated system of care. Yet, these children are most often treated in the general primary care setting, rather than within specialty clinics.¹⁹ Children often return to schools and communities for management of their TBI after their initial medical care; however, schools and community-based providers may not provide systematic and coordinated care, as they often lack education and understanding in the effects of a TBI on a developing brain.²⁰⁻²² Our current care system must be improved so that we can reduce the negative long-term consequences of pediatric TBI.

Although research regarding care coordination for pediatric TBI is scarce, the literature thus far has identified areas for potential improvement. Beginning in the intensive care unit, where children who are significantly impacted by TBI start their care journey, a retrospective cohort study found that use of a standardized care protocol improved discharge disposition and decreased mortality rate.²³ A small number of studies have surveyed and interviewed parents to better understand their perspective on long-term service provision for children with TBI. Lever et al.²⁴ found that schedule conflicts with other appointments and lack of resources, such as transportation and insurance issues, negatively impact family attendance at follow-up appointments in the first year after a child is hospitalized with a TBI. Two additional studies reported that parents felt overwhelmed with hospital-to-home transition due to the significant decrease in support and receipt of insufficient information regarding their child's recovery, available financial supports, and available services for the child and family.^{25,26} One qualitative study interviewed healthcare providers and found that providers felt that early implementation of

psychosocial interventions targeting communication, transition planning, and caregiver support would be beneficial in improving parental experiences with healthcare management and outcomes of children with severe TBI.²⁷ Continued support and education is especially vital for rural families, as they often have limited access to specialty health care providers and rely on primary care physicians (PCPs) for most medical care. PCPs have a broad scope of practice and often lack the training and experience to care for persons with complex medical conditions, including children with TBI.^{28,29} In order to mitigate the barriers of geographical location and limited qualified professionals, telehealth may be a promising tool for management of TBI.³⁰⁻³³ Since PCPs most often have initial contact with families following a TBI, implementation of TBI-specific trainings or tools for primary care practices may also enhance knowledge and resources for these physicians.^{34,35}

Although the literature pertaining to care coordination for youth with TBI has identified potential areas of improvement and suggested tools to address these areas, research evaluating the use of these tools to improve care coordination for children with TBI is lacking. Families of children with TBI require many of the same resources and services as families of children with other chronic medical conditions, as TBI fits the criteria for the Children with Special Health Care Needs (CSHCN) program³⁶ and qualifies as a chronic health condition in children.³⁷ Since long-term management of pediatric TBI currently lacks evidence-based guidelines to support the best methodology for care coordination, this scoping review aimed to identify care coordination tools utilized with CSHCN to provide guidance for future studies aimed at improving care coordination for children with TBI. The question guiding this scoping review was the following: What tools improve care coordination for CSHCN? Understanding care coordination tools deemed helpful for CSHCN can guide the design of prospective studies for children with TBI. This can help establish evidence-based strategies to improve communication, reduce unmet needs, increase service access, and improve long-term outcomes for children with TBI.

Methods

This scoping review follows the PRISMA framework and methodology for scoping reviews (PRISMA-ScR)³⁸ and is informed by scoping review methodology recommendations by Arksey and O'Malley³⁹ and Levac, Colquhoun, and O'Brien.⁴⁰ See Supplementary Material for completed PRISMA-ScR checklist.

Data sources and search strategy

The third and fourth authors, in coordination with a working group from the 2019 Galveston Brain Injury

Conference, generated ideas for possible search terms during phone conferences and interactive email exchanges. In January 2020, a medical librarian and the fourth author completed several practice searches using an iterative strategy to settle on final search terms. The following databases were included in our search: OVID/Medline, CINAHL, PsycINFO, EMBASE, and ERIC. Search terms are included in Table 1. Following the search, titles and abstracts were exported into Rayyan QCRI,⁴¹ a web-based program for systematic reviews.

Screening process

Researchers followed a 3-step screening procedure to determine the eligibility of the articles identified in the search. Titles and abstracts were first reviewed independently by 4 trained assessors: 3 undergraduate and 1 graduate student studying Speech and Hearing Science. Each title/abstract was reviewed independently by 2 abstracters, and the first author verified reliability and resolved any disagreements. Articles marked as “include” or “maybe” during this first stage were then collaboratively screened by 2 undergraduate students and the first and fourth authors. During this second phase, abstracters completed full-text reviews and came to consensus on whether each article met inclusion criteria for this scoping review. To ensure that our search captured as many relevant articles as possible, we examined the reference sections of included articles and the “similar articles” feature in Google Scholar.

Eligibility criteria

Inclusion criteria. Only empirical research studies (qualitative, quantitative, and mixed methods) were included in this scoping review. Included papers had to include an examination of at least 1 intervention related to care

coordination for CSHCN. Additionally, the study must have involved care for a person under 25 years of age (extended past the age of 18 since individuals may be able to receive services designated for children, such as special education, through their 25th birthday). When sample ages were not included, other descriptors were used to determine age eligibility such as location at a children’s hospital or care received by a pediatrician.

Exclusion criteria. Papers that were expert opinion, book chapters, dissertations, or conference abstracts were excluded, as were reviews that represented secondary research (i.e. scoping and systematic reviews, meta-analyses). Articles written in languages other than English were excluded. To capture the last decade of work related to this subject, articles published prior to 2009 were excluded. Articles that included a care coordination intervention that would not be relevant or applicable to children with TBI (e.g. focused or specific medical intervention related to a diagnosis) were also excluded.

Data extraction

Based on the purpose of this scoping review, researchers used a data extraction spreadsheet to record all relevant variables from each included study. Each paper was assigned to 1 of the 4 authors to review and tabulate. Data recorded from each paper included: (1) year of publication and location of study, (2) study aims, design, and population, (3) care coordination interventions and outcomes, (4) study results, and (5) additional notes or findings of interest (See Supplementary Material for the data extraction tool used in this study). To ensure reliability in data extraction, 20% of articles were reviewed by a second researcher. Point-by-point agreement was 88%. Because the goal of this study was to explore the body of research related to care coordination strategies used with CSHCN, researchers did not assess the scientific level of evidence of the intervention studies included in this review.

At this point in our scoping review, the authors identified 3 primary groups of care coordination studies that met inclusion criteria and addressed the primary question of our review: What factors improve care coordination for CSHCN? The authors determined that studies fell into 1 of 3 specific categories: (1) care coordination tools, (2) care coordinator roles (paper included in this issue), and (3) hospital-to-school care coordination. To most effectively and efficiently synthesize the existing research related to care coordination with CSHCN, we divided this scoping review into 3 distinct pieces to reflect the natural divisions present in the literature. This manuscript focuses specifically on studies that address the use of different care coordination tools to improve care for CSHCN, and

Table 1. Search terms.

| Research component | Research terms |
|----------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| #1 care coordination | (interdisciplinary communication) OR (interdisciplinary collaboration) OR (complex care manag*) OR (care coordination) OR (teacher communication) OR (interprofessional collaboration) OR (interprofessional communication) |
| #2 diagnoses | (medically complex child*) OR (special health care need*) OR (chronic medical condition*) OR (chronic medical illness) OR (complex care) OR (complex medical) |
| #3 | #1 AND #2 |

the remaining portions of the full review are available in companion publications.⁴²

Results

Figure 1 depicts our screening process and search results. Following the division of eligible articles into 3 scoping reviews as described above, 21 studies met criteria for inclusion in this scoping review focusing on care coordination tools used with CSHCN. Authors read and tabulated full-text articles as described above. Table 2 presents the study characteristics from the 21 articles, and Table 3 describes the outcomes and results of each study included in this review.

All studies were published between 2009 and 2018. Eighteen studies were conducted in the United States, 1 in the Netherlands, 1 in Australia, and 1 in Canada. Studies included CSHCN ages 0–25 years and/or their family members (e.g. caregivers). For this review, all study participants will be referred to as CSHCN, although some studies included narrower inclusion criteria. For more detailed information regarding sample characteristics and diagnoses, refer to Table 2. Sixteen studies used quantitative methods, 2 used qualitative methods, and 3 used mixed methods. Six major categories of care coordination tools were identified: telehealth, online health records and

tools, care plans, inpatient discharge protocols, family training, and reminders.

Telehealth

Telehealth is a growing form of health care delivery that allows for implementation of continuous and easily accessible health care services through use of telecommunication technologies, such as telephone and video chat. Six studies utilized telehealth as the main intervention for care coordination. Five of these studies utilized telehealth for patients and families,^{43–47} and 1 study utilized telehealth for providers.⁴⁸

Telehealth for patients and families. All studies that focused on telehealth for patients and families utilized registered nurses (RNs) for telehealth interactions. Telehealth aimed to address barriers in access to care for CSHCN such as distance from and insufficient numbers of specialty providers, lack of parental resources, cost of medical management, and care fragmentation. Studies used video and/or telephone coordination so that families could contact their care coordinator with questions or concerns about their child. In an examination of mode of telehealth delivery, Looman et al.⁴³ found no statistically significant differences in outcomes for families who used telephone versus video telehealth services. Caregivers reported improved

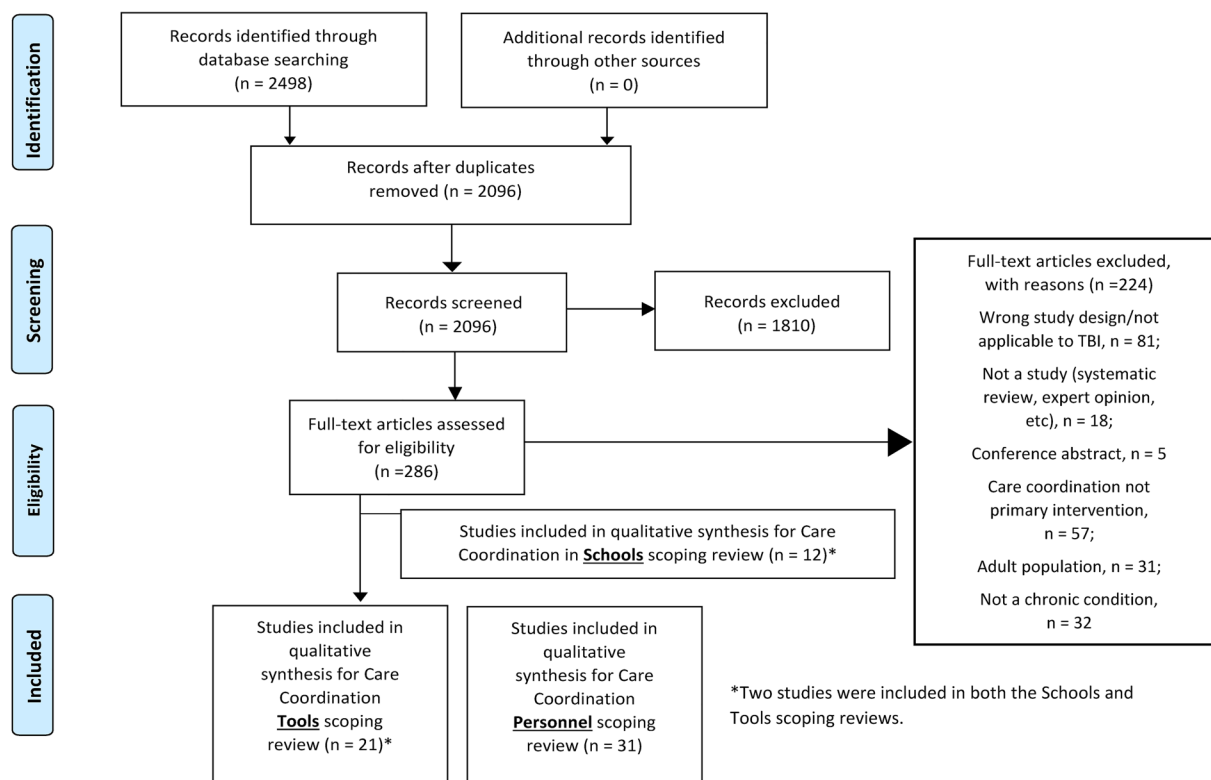


Figure 1. PRISMA diagram illustrating article selection procedures.

Table 2. Characteristics of studies included in this review.

| Study | Country of origin | Sample characteristics | Diagnoses | Professionals implementing the intervention | Type of study |
|-----------------------------------------|-------------------|------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------|---------------|
| <i>Telehealth as main intervention</i> | | | | | |
| <i>Telehealth for patients/families</i> | | | | | |
| Looman et al. (2015) | US | 2–15 years old ($n = 148$) | Medical complexity | APRN care coordinators | Mixed |
| Looman et al. (2018) | US | 2–15 years old ($n = 163$) | Medical complexity | APRN care coordinators | Quantitative |
| Cady et al. (2009) | US | 2–17 years old ($n = 43$) | Special health care needs | APRN care coordinators | Quantitative |
| Cady et al. (2014) | US | 2–17 years old ($n = 27$) | Medical complexity | APRN care coordinators | Mixed |
| Vessey et al. (2015) | US | Sample size and age not provided; treated by neurology or gastroenterology services | Complex chronic conditions | Ambulatory care registered nurses | Quantitative |
| <i>Telehealth for providers</i> | | | | | |
| Sarvet et al. (2010) | US | Sample size and age not provided | Mental health disorders | Child psychiatrists, child therapists, and care coordinators | Quantitative |
| <i>Online health records and tools</i> | | | | | |
| <i>Developed EHR</i> | | | | | |
| Bruns et al. (2018) | US | Children 5–18 years old ($n = 83$); Wraparound facilitators ($n = 34$) | Complex behavioral health needs | Wraparound facilitators | Quantitative |
| <i>Individual EHR/EMR tools</i> | | | | | |
| Geltman et al. (2015) | US | 5–18 years old ($n = 329$) | Attention deficit hyperactivity disorder | Health care team | Quantitative |
| Matiz et al. (2016) | US | 4–18 years old ($n = 1217$); primarily Hispanic and insured by Medicaid or Child Health Plus | Asthma | Health care professionals | Quantitative |
| <i>Online patient-centered tools</i> | | | | | |
| Tom et al. (2012) | US | Parents of children <5 years old ($n = 256$) | Chronic diseases (primarily asthma, congenital musculoskeletal abnormalities, congenital heart disease, inborn errors of metabolism, cystic fibrosis, and hereditary and acquired hemolytic anemias) | Health care team | Quantitative |
| Gulmans et al. (2010) | Netherlands | Parents of children ages 4–8 years old ($n = 30$); Health care professionals ($n = 120$) | Cerebral palsy | Health care professionals | Mixed |
| <i>Care plans</i> | | | | | |
| Ming et al. (2019) | US | Families of children ages 4 months–18 years old ($n = 50$) | Medical complexity | Multidisciplinary health care team | Mixed |
| McAllister | US | | Autism spectrum disorder; | Health care team | Quantitative |

(continued)

Table 2. Continued.

| Study | Country of origin | Sample characteristics | Diagnoses | Professionals implementing the intervention | Type of study |
|--------------------------------------|-------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------|---------------|
| et al. (2018) | | Families of children ages 2–10 years old ($n = 70$) | global developmental delay/ intellectual disability | (clinicians, coordinators, researchers, senior family leaders, administrators) | |
| Jones et al. (2019) | Australia | Mothers of children ages 3–6 years old ($n = 9$); Practitioners involved in an autism spectrum disorder early intervention service ($n = 11$) | Autism spectrum disorder | Parents and practitioners (teachers, therapists, family support workers) | Qualitative |
| Adams et al. (2013) | Canada | Parents of children ages <1–18 years old ($n = 15$); Health care providers ($n = 15$) | Medical complexity | Health care providers | Qualitative |
| <i>Inpatient discharge protocols</i> | | | | | |
| Statile et al. (2016) | US | Median age of 5.3 years ($n = 227$) | Medical complexity | Multidisciplinary health care team | Quantitative |
| Wright (2018) | US | Caregivers of infants with single ventricle physiology post-first stage palliative surgery in the cardiovascular intensive care unit ($n = 16$) | Congenital heart disease | Multidisciplinary health care team | Quantitative |
| Baker et al. (2016) | US | Children with chronic mechanical ventilation via tracheostomy ($n = 48$) | Chronic respiratory failure or insufficiency | Interdisciplinary health care team | Quantitative |
| <i>Family training</i> | | | | | |
| Seid et al. (2010) | US | 2–14 years old ($n = 252$); Primarily Hispanic and Spanish-speaking and of low socioeconomic status | Persistent asthma with no comorbid conditions | Bilingual, bicultural asthma home visitors | Quantitative |
| <i>Reminders</i> | | | | | |
| McPhail et al. (2010) | US | Children with inpatient pulmonary consultations ($n = 211$) | Chronic respiratory diseases (asthma, community-acquired and/or complicated pneumonia, aspiration pneumonia, obstructive sleep apnea) | Administrative assistants | Quantitative |
| Wagner et al. (2016) | US | Youth with repeat diabetic ketoacidosis ($n = 26$); Primary caregivers ($n = 24$); Interventionists ($n = 8$) | Diabetes | Masters-level interventionists with medical, psychology, public health, and/or social work background | Quantitative |

APRN: advanced practice registered nurse.

satisfaction with medical care and provider communication,⁴³ and RNs felt it was beneficial to teach parents how to more independently monitor and manage their child's health.⁴⁶ Telehealth also decreased rates of unplanned inpatient hospitalizations^{45,46} and unnecessary clinic visits.⁴⁷ Vessey et al.⁴⁷ found that majority of the care coordination

calls required the expertise of an RN, and that use of an RN to address family questions resulted in more cost-effective care by reducing physician involvement.

Studies implementing telehealth for CSHCN reported some non-significant findings as well. Looman et al.⁴³ found no statistically significant difference between usual

Table 3. Care coordination tools outcomes and results from studies included in this review.

| Study | Data collection/outcomes | CC interventions | Results |
|-----------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>Telehealth as main intervention</i> | | | |
| <i>Telehealth for patients/families</i> | | | |
| Looman et al. (2015) | <ul style="list-style-type: none"> Primary caregiver satisfaction with health care via 7 measures from the Consumer Assessment of Healthcare Providers and Systems survey Help discrepancy score via 2 visual analog scales | APRN telehealth care coordination was implemented. Study groups included a usual care control group, an APRN-delivered, telephone-based care coordination intervention group, and an APRN-delivered, telephone plus interactive video-delivered care coordination intervention group. | <ul style="list-style-type: none"> Statistically significant intervention effect for dimensions of satisfaction related to provider engagement with the child and family but not for measures that asked about receiving needed care and receiving care quickly No statistically significant differences in satisfaction-related outcomes or relative benefits of one mode of intervention over the other (telephone versus video) |
| Looman et al. (2018) | <ul style="list-style-type: none"> HRQL via the Pediatric Quality of Life Inventory Functional status of the child via the Functional Status II(R) | APRN telehealth care coordination was implemented. Study groups included a usual care control group, an APRN-delivered, telephone-based care coordination intervention group, and an APRN-delivered, telephone plus interactive video-delivered care coordination intervention group. | <ul style="list-style-type: none"> No statistically significant improvements in HRQL scores in intervention groups There was a statistically significant association between child HRQL and condition characteristics (i.e. neurologic impairment, technology dependence, condition stability) Child HRQL was also associated with parent physical, cognitive, and social functioning |
| Cady et al. (2009) | <ul style="list-style-type: none"> Number of planned & unplanned hospitalizations | A team of 2 APRNs provided telephone-based, comprehensive care coordination and case management to CSHCN. | <ul style="list-style-type: none"> Decline in normalized rates of unplanned inpatient days Normalized rates of planned inpatient days remained fairly constant |
| Cady et al. (2014) | <ul style="list-style-type: none"> Type, frequency, content, and perceptions of care coordination episodes via: <ul style="list-style-type: none"> In-person interviews with 2 APRNs Retrospective review of clinical care coordination documentation Program-specific survey mailed to parents | Relationship-based APRN care coordination was conducted exclusively by telephone with the exception of annual clinic visits. | <ul style="list-style-type: none"> Parents appreciated a single place to call for assistance and someone to clarify and coordinate care amongst their child's multiple providers Majority of parents "strongly agreed" their child was not sick as long and had fewer hospitalizations since joining the program |
| Vessey et al. (2015) | <ul style="list-style-type: none"> Cost of care Care Coordination Measurement Tool used to collect: <ul style="list-style-type: none"> Types of services delivered Nurses' ability to resolve patient/family concerns Decreases in the number of unnecessary patient visits | Patient/family-initiated telephone encounters were managed by ambulatory care RNs through: (1) direct intervention; (2) in consultation with providers or another service; or (3) referral. | <ul style="list-style-type: none"> Number of unnecessary patient visits decreased without adverse outcomes Majority of calls required RN clinical expertise/advice By utilizing RNs and preventing unnecessary physician involvement, time and compensation were saved |
| <i>Telehealth for providers</i> | | | |
| Sarvet et al. (2010) | <ul style="list-style-type: none"> Consultation team encounters via data logged by PCPs PCP satisfaction with services via a baseline and follow-up survey | Through a telephone hotline, regional consultation teams provided PCPs with rapid access to child psychiatry expertise, education, and referral assistance. | <ul style="list-style-type: none"> Increased PCP perception of adequate and timely access to a child psychiatrist Increased PCP confidence in ability to meet needs of children with psychiatric problems |

(continued)

Table 3. Continued.

| Study | Data collection/outcomes | CC interventions | Results |
|----------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>Online health records and tools</i> | | | |
| Developed EHR | | | |
| Bruns et al. (2018) | <ul style="list-style-type: none"> Via web surveys and phone interviews, facilitators reported on: <ul style="list-style-type: none"> EHR usability and appropriateness Supervision processes and activities Work satisfaction Use of and attitudes toward standardized assessments Via phone interviews parents reported on: <ul style="list-style-type: none"> Fidelity, quality, and satisfaction with behavioral health care | Examination of wraparound facilitators' use of an EHR versus paper-based charting | <ul style="list-style-type: none"> 50% of cases kept by PCPs for follow-up psychiatric care EHR group spent more time reviewing and applying client progress and less time on administrative tasks and reminders Mean ratings of overall EHR usability were low Pattern of poorer scores for EHR group related to clinician and client alliance Perceptions of the psychometric quality of standardized assessments improved for the paper-based group but not the EHR group |
| Individual EHR/EMR tools | | | |
| Geltman et al. (2015) | <ul style="list-style-type: none"> Percentage of patients receiving medication and appropriate follow-up care via Healthcare Effectiveness Data and Information Set measures Use of Vanderbilt rating scales | An electronic registry of patients with ADHD was used in combination with care coordination by a planned care team. Clinical work flows were created in the EMR to facilitate the use of Vanderbilt scales and to monitor patient care and follow-up. Care teams met monthly to review each patient's report and determine the need for follow-up or clinical monitoring. | <ul style="list-style-type: none"> Modest improvements in the diagnostic and treatment process for patients with ADHD Increased follow-up care for patients who were newly prescribed medication Improved use of standardized assessment tools |
| Matiz et al. (2016) | <p>At baseline and each year (over a span of 3-years) the following was obtained:</p> <ul style="list-style-type: none"> Number of ED visits Number of inpatient admissions | In order to improve asthma outcomes, a disease registry was established for children with asthma and asthma-specific modifications were made to notes, care plans, and orders in the EHR. | <ul style="list-style-type: none"> Reduction in ED visits and inpatient admissions Improved workflow across the entire medical home and for all patients with asthma Increase in referrals to the community health worker care coordination program, especially for high-risk patients |
| Online patient-centered tools | | | |
| Tom et al. (2012) | <ul style="list-style-type: none"> PHR use patterns via dichotomous responses to survey questions pertaining Primary care access and experiences via the Consumer Assessment of Healthcare Providers and Systems survey | An integrated (i.e. linked to the patient's EMR) PHR was used to improve patient-centered access to care. PHR services included: secured messaging, medical record viewing, medication management, and appointment management. | <ul style="list-style-type: none"> Use of an integrated PHR did not appear to improve care experiences Majority of parents used the PHR during the study period, especially in viewing the child's immunizations, viewing the medical record, and secured messaging |
| Gulmans et al. (2010) | <ul style="list-style-type: none"> System use data Parents' and professionals' experiences using the web-based communication system via user experience questionnaires | A secure, web-based communication system for parent-professional and inter-professional communication was used to improve communication in the care of children with cerebral palsy. | <ul style="list-style-type: none"> Parental use of the system exceeded professional use The number of professionals involved in a child's care network was higher at statistically significant |

(continued)

Table 3. Continued.

| Study | Data collection/outcomes | CC interventions | Results |
|-------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | | | <p>levels for parents who used the system</p> <ul style="list-style-type: none"> • Reported improvements in parent-professional and inter-professional communication • User feedback requested improved ease of use and linking with existing patient documentation |
| <p><i>Care plans</i> Ming et al. (2019)</p> | <p>Quantitative outcomes included:</p> <ul style="list-style-type: none"> • Feasibility of implementation • Parental engagement • Communication timeliness • Reading messages <p>Qualitative outcomes were obtained via semi-structured interviews pertaining to:</p> <ul style="list-style-type: none"> • Family engagement with plan • Benefits of plan for CMC • Factors that impacted use of plans | <p>A mobile complex care plan integrated within the EHR was used to facilitate communication between care providers and parents of CMC.</p> | <ul style="list-style-type: none"> • Mobile complex care plans were feasible, facilitated parental engagement, and delivered timely communication with the care team • Parents reported that mobile complex care plans improved their understanding of their child's overall medical situation |
| <p>McAllister et al. (2018)</p> | <p>Via family surveys and a Shared Plan of Care the following outcomes were obtained:</p> <ul style="list-style-type: none"> • Care coordination access • Families' perception of team collaboration • Unmet needs • Family goal types and status • Family partnerships • Family empowerment • Family worry | <p>A co-produced Shared Plan of Care, a family-centered, team-based guide to care coordination activities, was used.</p> | <ul style="list-style-type: none"> • Use of a Shared Plan of Care was feasible and effective • Facilitated goal identification and progress • Reduced unmet needs • Increased family empowerment • Reduced family worry regarding their children's health |
| <p>Jones et al. (2019)</p> | <ul style="list-style-type: none"> • Parents' and practitioners' perspectives on usage of the goal setting tool via semi-structured interviews and focus groups | <p>Family Goal Setting Tool: Autism Spectrum Disorder Version was used to support family identification and prioritization of goals and collaborative engagement in goal setting meetings.</p> | <ul style="list-style-type: none"> • Participants recommended continued use of the tool • The tool was perceived to facilitate a comprehensive approach, collaboration, goal prioritization, and relieve the stress of goal setting for mothers • Practitioners reported the tool empowered families and enabled family-centered practice & was clinically useful |
| <p>Adams et al. (2013)</p> | <ul style="list-style-type: none"> • Parents' and health care providers' perceptions of comprehensive care plans via semi-structured interviews and focus groups | <p>Template-based comprehensive care plans outlined CMC's major medical issues and care needs to assist with care coordination. The care plan was created by a pediatric nurse practitioner in collaboration with the family and was integrated into the child's EMR. It was updated at</p> | <ul style="list-style-type: none"> • Parents stressed the importance of including social aspects of their child's condition into the care plan • Participants perceived positive outcomes including strengthened relationships, enhanced information sharing, clarification of |

(continued)

Table 3. Continued.

| Study | Data collection/outcomes | CC interventions | Results |
|--------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | | clinic visits and during inpatient admissions. | <ul style="list-style-type: none"> professional and parental roles and responsibilities, and quality care Parents felt less stressed when relying on a care plan for information as opposed to having to recount details of their child's medical history |
| <i>Inpatient discharge protocols</i> | | | |
| Statile et al. (2016) | <ul style="list-style-type: none"> Percentage of patients discharged within 2 h of meeting their medical discharge goals Pre- and post-intervention LOS 30-day readmission rate | In order to improve discharge efficiency of CMC, a multidisciplinary team defined medical discharge goals on admission for each patient and implemented a complex care inpatient team, an electronic admission order set, weekly care coordination rounds, a needs assessment tool, and a medication pathway. | <ul style="list-style-type: none"> Increased percentage of patients discharged within 2 h of meeting medical goals Median LOS and 30-day readmission rate were not impacted, indicating patients were not discharged prematurely Providers perceived workload decompression Standardizing discharge planning processes and identifying discharge barriers early were the most impactful interventions |
| Wright (2018) | <ul style="list-style-type: none"> Parental understanding of nesting and feelings of preparedness upon discharge via pre- and post-intervention caregiver satisfaction surveys Readmission rates via retrospective chart review | A nesting protocol that allowed parents to practice assuming complete care of their child in a simulated home environment prior to leaving the hospital was created to improve discharge teaching and care coordination. The protocol designated a 24–48 h period before discharge for 2 caregivers to assume complete care of the child while in a safe setting. | <ul style="list-style-type: none"> Caregivers reported an increase in satisfaction and understanding of the nesting process No improvement in readmission rates Caregivers reported inconsistency in implementation of the protocol |
| Baker et al. (2016) | Pre- and post-intervention: <ul style="list-style-type: none"> LOS Mortality rate Number of ED visits Unplanned readmission rates Per-patient hospital costs | An Interdisciplinary Ventilator Care Program team developed and utilized a standardized discharge process for children who require chronic ventilation that included: educational materials, a Chronic Ventilation Road Map for caregivers, tracking discharge readiness, team-based care coordination, and timely case management to arrange home nursing. | <ul style="list-style-type: none"> Statistically significant reductions in overall LOS and hospital costs with no negative impact on patient safety Morbidity and mortality did not increase as a result of the shorter hospitalization |
| <i>Family training</i> | | | |
| Seid et al. (2010) | Outcomes were measured pre- and post-treatment and at a 6-month follow-up: <ul style="list-style-type: none"> Parent report of child's generic HRQL Child reported generic HRQL Asthma symptoms Asthma-related utilization | A standard care control group received ongoing asthma care. A care coordination group received 5 weekly home visits from paraprofessionals who implemented a structured set of asthma-specific educational interventions with written materials, made referrals as necessary, and communicated with PCPs. A problem-solving skills training group received care coordination and 6 weekly | <ul style="list-style-type: none"> A statistically significant & clinically important difference was detected in parent-reported child HRQL in the problem-solving skills training group compared to the standard care group No statistically significant effects for child-reported HRQL, asthma-specific HRQL, or daytime symptoms Though the sample size was too small to detect a statistically |

(continued)

Table 3. Continued.

| Study | Data collection/outcomes | CC interventions | Results |
|-----------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | | problem-solving skills training interventions that aimed to normalize problems and train parents to independently solve them. | significant difference, children in the problem-solving skills training group were half as likely to have an emergency, inpatient, or unscheduled office visit |
| <i>Reminders</i> | | | |
| McPhail et al. (2010) | <ul style="list-style-type: none"> • Clinic follow-up rates | To improve clinic follow-up rates, simple care coordination interventions were implemented including: direct mail reminders, discharge summary reminders, follow-up appointment establishment via an administrative assistant, appointment dates included in discharge summaries, and automated phone call reminders within 72 h of appointments. | <ul style="list-style-type: none"> • Direct mail reminders were not successful • Discharge summary reminders increased follow-up rates • Establishing follow-up appointments and including appointment dates in discharge summaries in combination with providing reminder phone calls resulted in greatest follow-up improvements |
| Wagner et al. (2016) | <p>Outgoing texts were monitored for the following:</p> <ul style="list-style-type: none"> • Time sent • Micro level intervention • Macro level intervention • Primary content codes • Secondary content codes • Care type codes | To increase patient and family contact, provide reinforcement for diabetes management, assist with problem solving, build rapport, and provide skills coaching personalized text message interventions were used with youth with diabetes and their caregivers by interventionists who were on call 24/7. | <ul style="list-style-type: none"> • Majority of outgoing texts occurred outside of typical business hours • Behavioral intervention text messages were typically sent outside of business hours and care coordination and case management text messages during business hours |

APRN: advanced practice registered nurse; HRQL: health-related quality of life; CSHCN: children with special healthcare needs; PCP: primary care physician; EHR: electronic health record; EMR: electronic medical record; ADHD: attention deficit hyperactivity disorder; ED: Emergency Department; PHR: personal health record; CMC: children with medical complexity; LOS: length of stay.

care and telehealth intervention groups on receipt of needed care or on receiving care more quickly. Telehealth interventions also did not appear to have a statistically significant impact on health-related quality of life (HRQL).⁴⁴ More severe and complex conditions were associated with poorer child HRQL, and poor child HRQL was associated with lower parental functioning scores.⁴⁴ Thus, condition severity and complexity appeared to be barriers to care coordination. While telehealth appeared to decrease unplanned hospitalizations, as mentioned above, in one study, it did not impact the rates of planned hospitalizations.⁴⁵

Telehealth for providers. Using encounter-related data and baseline and follow-up surveys, Sarvet et al.⁴⁸ examined use of a telephone hotline for PCPs to access child psychiatry expertise. The study aimed to address barriers to care including PCP need for assistance from specialty services. The telephone hotline provided PCPs with easy access to support from specialists and resulted in PCPs maintaining

care for 50% of patients with mental health needs. Use of telehealth for health care providers appeared to address PCPs' need for specialty service consultations and facilitate care coordination for CSHCN.

Online health records and tools

Five studies used online health records and tools as a main care coordination intervention for CSHCN. One study developed a new electronic health record (EHR) for this purpose.⁴⁹ Two studies used individual EHR/electronic medical record (EMR) tools,^{50,51} and 2 studies used online patient-centered tools.^{52,53}

Developed EHR. Bruns et al.⁴⁹ conducted a randomized controlled trial that compared use of an EHR developed to facilitate implementation of care coordination versus paper-based charting. The study was motivated by barriers to care including incomplete record keeping, inefficient access to documentation, and insufficient information

sharing and coordination of care for CSHCN. The study also aimed to address barriers specific to implementing EHRs including time for training and adoption, cost for procurement and maintenance, and technical support for use. Use of an EHR, compared to paper-based charting, allowed more time to be spent on client progress rather than on administrative tasks. However, clinicians perceived the psychometric quality of standardized assessments to be poorer in the EHR group and reported low usability ratings for the EHR. There was also a pattern of lower scores reported from parents in the EHR group related to clinician and client alliance. Therefore, use of an EHR appeared to facilitate care coordination, but barriers to EHR adoption persisted, complicating the usability of this care coordination tool.

Individual EHR/EMR tools. Studies that used individual EHR/EMR tools aimed to standardize care processes and improve care coordination by embedding developed tools into the EHR or EMR. EHR/EMR tools attempted to address care coordination barriers including disparities in diagnosis, treatment, and use of services, inadequate adherence to best practice guidelines, and difficulties associated with implementation of a medical home for CSHCN.^{50,51} These tools increased follow-up care for patients who were newly prescribed medication⁵⁰ and improved use of care plans and standardized assessment tools by medical providers.^{50,51} Matiz et al.⁵¹ also showed that online tools for providers reduced emergency department and hospital utilization and increased referrals to a care coordination program.

Online patient-centered tools. Patient-centered online tools provide caregivers of CSHCN access to their child's medical record and care resources. These interventions were used in response to identified lack of access to a medical home, gaps in preventative care for CSHCN, and complicated coordination of care amongst multiple providers and with caregivers. Gulmans et al.⁵² found that a web-based communication system for parents and medical providers was feasible and improved parent-professional and inter-professional communication. Specifically, they found that between parents who used the system and those who did not there was a statistically significant difference in the number of professionals involved in their child's care. Children of parents who used the system had an increased number of individuals involved in their care, indicating the system was more useful for parents of children with more complex needs. However, parents and providers felt the system's ease of use could be improved and should be linked with existing patient documentation. Tom et al.⁵³ found that parents did not report improved health care access or experiences when an online health record was integrated into the child's EMR.

Care plans

Four studies used care plans as the main care coordination intervention.^{54–57} Care plans were collaborative documents, accessible to families and professionals that included major medical issues, care needs, and goals to improve communication and coordination within a child's care network. All studies incorporated families into care plan creation and use and addressed the identified care coordination barriers of lack of family involvement in planning and care and poor provider/service coordination. Aiming to improve ease of communication between caregivers and medical providers, studies found an increase in parental engagement and empowerment,^{54,55,57} more timely communication,⁵⁴ facilitation of goal identification and progress,^{55,56} stronger relationships between caregivers and providers,⁵⁷ and a reduction of unmet needs.⁵⁵ Jones et al.⁵⁶ specifically noted that their care plan tool was particularly useful for parents who may be on the autism spectrum themselves, were unsure of their priorities, or were just beginning to learn about their child's autism diagnosis. The care plans were found to be empowering for parents with English as a second language or limited literacy due the collaborative, engaging nature of the goal setting process.

Inpatient discharge protocols

Three studies used inpatient discharge protocols as the main tool for care coordination.^{58–60} Protocols standardized the discharge process in order to improve discharge efficiency by defining discharge goals, identifying and addressing home needs early, and increasing communication and collaboration among professionals. All 3 studies focused on inpatient discharge protocols as a strategy to improve care coordination by addressing barriers associated with extended inpatient stays for CSHCN. Use of inpatient discharge protocols resulted in improvements in discharge efficiency⁵⁸ and identification of parental care/home needs.^{58,59} Baker et al.⁶⁰ also found that a standardized discharge process resulted in decreased inpatient length of stay and lower hospital costs with no negative impact on patient safety. Two of the 3 studies, however, found no statistically significant decrease in rates of hospital readmission.^{58,59}

Family training

Although several studies included family training in their care coordination intervention, only one examined family training in isolation.⁶¹ Seid et al.⁶¹ examined the effects of disease-specific education, coordination of care services, and problem-solving training for parents of CSHCN. The study was in response to the high burden of illness, low HRQL, and the medical challenges that CSHCN face in daily life. Implementation of family training and education improved parents' perceptions of their children's general

HRQL and appeared to decrease health care utilization (i.e. Emergency Department visits, hospitalizations, unscheduled clinic visits), although differences in health care utilization between the problem-solving training group and control group were not statistically significant due to the small sample size.

Reminders

Two studies used family or patient reminders as the main care coordination intervention.^{62,63} Both studies aimed to address poor treatment management and medical follow-up of CSHCN. McPhail et al.⁶² found that establishing follow-up appointments and providing reminder phone calls to families resulted in improvements in clinic follow-up rates, but direct mail reminders were not successful. Use of follow-up reminders in discharge summaries also improved follow-up but less so than establishing follow-up appointments and providing reminder phone calls. Wagner et al.⁶³ found that use of personalized text messaging for adolescents and young adults was beneficial and suggested the need for care assistance beyond traditional business hours. The researchers suggested that text message intervention may be most useful for providing behavioral intervention and care coordination, specifically in providing positive interactions and addressing scheduling needs.

Discussion

The purpose of this scoping review was to examine care coordination tools that have been trialed in studies with CSHCN to inform effective care coordination strategies for future studies related to children with TBI. Care coordination tools facilitate the organization of patient care activities between at least 2 individuals to improve delivery of health care services.¹⁰ Based on findings from studies included in this review, examining the use of telehealth, EHR/EMR embedded tools specific to pediatric TBI, enhanced care plans, and specific and accessible family training appear to have the greatest potential as useful care coordination tools for children with TBI to address gaps currently impeding pediatric TBI care coordination.

Although telehealth has previously been cited as a useful tool for assessment and intervention for children with TBI and their families,³⁰⁻³³ there is minimal research regarding telehealth as a tool to specifically facilitate care coordination activities. The evidence from the studies in this review support the potential utility of telehealth in managing care coordination for CSHCN, families, and health care providers, which could be translated into future research for children with TBI. With the use of experienced medical professionals, such as RNs, to deliver telehealth services, efficient and cost-effective health care services can be delivered to populations with complex medical needs. In one review, several studies revealed that as a

result of using telehealth for direct patient care or as a support for local primary care and hospitals, children received more appropriate care and referrals to specialists.⁶⁴ Use of telehealth may address barriers families face to access appropriate care for children with TBI created by the regionalization of pediatric health care services. Additionally, telehealth could potentially address barriers to care such as scheduling conflicts and lack of resources.²⁴ Offering telehealth appointments could decrease scheduling and resource barriers by eliminating the need for transportation and childcare and allowing convenient access to appointments from home. Telehealth is also a potential solution to address gaps in PCPs' knowledge and resources, as PCPs are frequently expected to care for children with TBI but often lack the support to do so effectively.^{28,29} By providing telehealth consultations with specialty health care providers, PCPs have the potential to more holistically address the needs of children with complex conditions, like TBI.^{50,51}

To further support PCPs, EHR/EMR tools specific to TBI could improve the quality and consistency of care for children with TBI and provide PCPs with the necessary supports to care for this complex population. The EHR/EMR tool interventions implemented in the 2 studies included in this review seem to match the existing TBI literature's call for tools to specifically enhance knowledge and resources for PCPs in caring for children with TBI.^{19,34,35} Similar to the positive results of the studies included in this review, a primary care-based intervention to improve youth concussion management resulted in more consistent and systematic implementation and documentation of recommended concussion management strategies.³⁴ Modifying established EHR/EMR systems to tailor them to the needs of specific populations appears to be more advantageous and reasonable than creating a novel EHR system for care coordination⁴⁹ or using an integrated personal health record.⁵³ Additionally, online patient-centered tools may be useful for families of children with TBI with consideration for the following capabilities: intuitive operation, messaging capability, and visibility of patient documentation.

Care plans may be useful in medical management of children with TBI by providing coordinated care between professionals. Care plans also have the potential to improve parental understanding of their child's medical condition and relieve parental worry by providing easily accessible documentation related to their child's overall condition and goals. For children with TBI, this may be crucial because a barrier parents report to seeking follow-up care includes lack of full understanding about their child's diagnosis and the potential long-term effects.²⁴ Care plans may help to decrease the unmet and unrecognized needs of children with TBI by explicitly identifying and documenting a child or family's needs through group collaboration with medical professionals.

The results from the studies examining implementation of inpatient discharge protocols in this review are consistent with the promising results of the study by O'Lynnner et al.²³ conducted with children with TBI. Improving the consistency of care during inpatient hospitalization could improve outcomes for children with TBI, as they are often discharged from acute hospitalization without inpatient or outpatient rehabilitation,^{16,17} relying on parents to coordinate the complicated care that these children might require. By improving parental education during initial medical encounters, parents can be better equipped to care for their child with newly complex needs. Although many children with TBI are not admitted to hospitals, use of inpatient discharge protocols may be a useful tool for children with more severe TBIs that are hospitalized.

Currently, after their child sustains a TBI, parents report a lack of support and limited education upon transitioning home from initial hospitalization,^{25,26} and gaps in knowledge and unclear pathways to care have been shown to impact TBI follow-up appointment attendance.²⁴ Wade et al.⁶⁵ conducted a family-focused problem-solving intervention with parents of children with TBI and found the intervention positively impacted parental adaptation after TBI. Improving parental education and training has the potential to increase routine follow-up care, decrease parental worry, and improve unmet or unrecognized needs of children with TBI, as parents will be more equipped to identify and respond to their child's needs. Parents of children with TBI report unmet information needs across the care trajectory with increased difficulty absorbing and recalling information at particularly points in time, such as immediately after their child's injury.²⁶ Therefore, appropriate timing and dispersion of education and training should be explored in future work.

Appointment reminders may be useful for care coordination in pediatric TBI, as many children do not follow-up with PCPs or specialty providers after acute hospitalization.^{15,66} As studies included in this review show, assistance and support in the form of reminders for children with TBI and their families could help to address the extra challenges associated with caring for a child with TBI, as many parents of children with TBI feel under-supported and overwhelmed after hospital discharge.^{25,26} Text message interventions specifically may provide a simple and convenient way to provide appointment reminders and clarifications to increase attendance at follow-up appointments.

As a scoping review, this work seeks to synthesize existing research on a broad topic; therefore, no definitive conclusions or recommendations can be made to directly change clinical practice at this time. As with all scoping reviews, it is possible that appropriate articles were not included in our review based on limitations in search terms and strategies. To extrapolate our findings to the population of children with TBI, we included search terms for chronic and complex health care needs but did not include specific diagnoses to ensure our search captured

broadly existing intervention studies focused on CSHCN. It is possible that these decisions, including that of only identifying papers published in the last decade, restricted the studies we found to meet our inclusion criteria. Despite these limitations, because the included intervention studies cover a breadth of possible care coordination tools and focus on a variety of pediatric medical diagnoses, we believe this scoping review is a good representation of available care coordination studies focusing on CSHCN.

This scoping review summarizes the current literature on tools trialed with CSHCN to improve care coordination. This information is relevant to the management of pediatric TBI, as childhood TBI is a chronic medical condition³⁷ and fits the criteria for the CSHCN program.³⁶ Telehealth, EHR/EMR tools, online patient-centered tools, care plans, inpatient discharge protocols, family training, and reminders appeared to improve care coordination for CSHCN and, therefore, may benefit care coordination for children with TBI. Use of these care coordination tools in the pediatric TBI population has the potential to improve current care systems' management of pediatric TBI to reduce unmet needs and improve long-term outcomes for this population by addressing the barriers currently impeding care coordination.

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Supplemental material

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