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Cara Palusak
Ohio University Dublin Campus

Brandy Shook
Ohio State University

Susan C. Davies
University of Dayton, sdavies1@udayton.edu

Jennifer P. Lundine
Ohio State University, lundine.4@osu.edu

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

Cara Palusak, B.S.¹

Brandy Shook, B.A.²

Susan C. Davies, Ed.D.³

Jennifer P. Lundine, Ph.D., CCC-SLP^{2,4}

1. Heritage College of Osteopathic Medicine, Ohio University Dublin Campus, Columbus, OH
2. Department of Speech & Hearing Science, The Ohio State University, Columbus, OH
3. Department of Counselor Education and Human Services, University of Dayton, Dayton, OH
4. Division of Clinical Therapies & Inpatient Rehabilitation Program, Nationwide Children's Hospital, Columbus, OH

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Corresponding author: Jennifer Lundine, 110 Pressey Hall, 1070 Carmack Rd., Columbus, OH 43210; phone: 614-292-1977; email: Lundine.4@osu.edu

ABSTRACT

BACKGROUND: Effective, patient-centered care coordination has been shown to improve outcomes for children with special healthcare needs (CSHCN), who often have complex, long-term involvement with multiple service providers. Traumatic brain injury (TBI) can result in long-term physical, intellectual, social, and emotional disabilities that persist long after acute treatment. Yet, even though it is a chronic condition, TBI remains an area with scarce standardization and research surrounding the complex, long-term care coordination need in this population. The purpose of this scoping review is to summarize current research on outcomes in CSHCN after implementation of care coordinators, whether individual or teams, to inform future research for youth with TBI.

METHODS: OVID/Medline, CINAHL, PsycINFO, EMBASE, and ERIC databases were searched for articles relevant to care coordination and CSHCN.

RESULTS: 31 articles met inclusion criteria. Outcomes for children and families were grouped into 5 major categories: healthcare utilization, cost of care, disease status, parent and child quality of life, and healthcare satisfaction and perception of care.

CONCLUSIONS: Implementation of care coordinators, whether in the form of individuals, dyads, or teams, resulted in overall positive outcomes for CSHCN and their families across all 5 major outcome domains. Future research should be focused on the efficacy of care coordinators differing in profession, qualifications, and educational attainment specifically for the unique needs of children with TBI. Additionally, the application of care coordination within medical homes should be further investigated to increase proactive, preventative care of children with TBI and further reduce reactive, need-based treatment only.

Introduction

Care coordination in the pediatric population is a key element in providing effective, patient-centered care across a multitude of systems and institutions during the child's life.¹

Care coordination is holistically 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 appropriate delivery of health care services.”² Care coordination is commonly delivered in the context of a Patient-Centered Medical Home (PCMH) and encompasses compassionate, team-based, informed care between healthcare workers, social work, educators, community partnerships, families, and others that bridge the gap between services.^{1,3,4}

Children with special healthcare needs (CSHCN) are a subset in particular need of competent care coordination due to their high risk of physical, emotional, social, and developmental chronic illnesses that require continued, multidisciplinary care for both the child and their family.^{3,5} While documented to have greater healthcare utilization globally, CSHCN require more comprehensive care and are less likely to receive all necessary healthcare services, showing significantly higher rates of unmet needs in both routine care and subspecialty care.⁵⁻⁷ Patient-provider care coordination decreases fragmentation in care, delays in treatment, adverse reactions, emergency department visits, and missed appointments and improves patients' perceptions of both past and future care.^{1,8-10} Overall, the lack of consistent care coordination in the pediatric healthcare system^{1,4} has been the basis of increasing research about barriers to care coordination and implementation in practice. Recently, the Commonwealth Fund Report,⁴ Care Coordination Measures Atlas,¹¹ and the National Academy

for State Health Policy¹² have described competencies, guidelines, and standardization for implementing care coordination in PCMHs; however, there is still little research on how interventions provided by care coordinator personnel might impact outcomes within specific pediatric chronic illnesses.

One such diagnosis that has received little attention in care coordination research is traumatic brain injury (TBI). TBIs are relatively common in the pediatric population ranging between 47-280 per 100,000 children worldwide.¹³ A TBI results from a blow, bump, jolt, or penetrating injury to the head that can result in significant disruption of normal brain functioning.¹⁴ A 2012 study found that 61.6% of children with moderate-to-severe TBI received new medical or therapy services within 12 months of injury compared to 14.3% of children with mild TBI; however, due to the incidence of mild TBI greatly exceeding moderate-to-severe TBI, the rate of new services for mild TBI was 9 times greater than moderate-to-severe TBI in total.¹⁵ This demonstrates the significant public health burden TBI poses in the pediatric population. Although research examining long-term outcomes post-TBI is limited,¹⁴ studies have shown that deficits and disability can persist post-injury.¹⁶⁻¹⁸ A TBI occurring during periods of brain development in childhood and adolescence results in the possibility of post-injury physical, cognitive, emotional, and social deficits affecting daily functioning.¹⁴ Pediatric quality of life (QoL) measures demonstrate a decrease in reported QoL post-TBI, with poorer QoL associated with increased severity of TBI, increased time since injury, older age, and more reported symptoms.^{17,18} With the clear public health burden and long-term potential for disability that TBI places on the pediatric population, young people with TBI fall under the broad definition of CSHCN,¹⁴ encompassing children “who have or are at increased risk of a

chronic physical, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”¹⁹ Because of the complex, long-term needs youth with TBI might experience, as in CSHCN, it is imperative that providers improve care coordination for children who sustain a TBI.

The 2018 Centers for Disease Control and Prevention Report to Congress emphasizes the lack of care coordination and standardization in long-term management of pediatric TBI despite its meeting criteria for classification as a chronic health condition.¹⁴ The insufficient application of care coordination is demonstrated by the low rates of routine pediatric primary care usage within one year of TBI²⁰ and lack of formal reporting systems for tracking long-term medical and nonmedical management of pediatric TBI.¹⁴ The absence of care standardization following pediatric TBI results in inconsistent referrals for rehabilitation services,²¹ which may lead to unmet needs for the child and their family. Although studies describing unmet and unrecognized needs post-TBI are well-documented,²² there is little research surrounding identification and resolution of these needs within and outside of the healthcare system.¹⁴ The paucity of consistent care coordination and standards of care throughout acute and long-term TBI recovery, along with unmet and unrecognized needs, has serious implications for caregivers, who face the daunting challenge of being the primary advocate for their child. The sudden onset of injury and assumption of new caregiving roles results in significant increases in caregiver and familial stress.²³ Improvements to care coordination to facilitate comprehensive and coordinated care for the child with TBI could help to alleviate parental stress and improve long-term outcomes for the child.

With pediatric TBI meeting criteria for classification as a chronic condition¹⁴ and care coordination showing positive outcomes among CSHCN suffering from chronic illnesses,^{8–10} more research is needed in the field of pediatric TBI to direct coordination of care throughout short and long-term recovery. This scoping review summarizes current research on child and family outcomes when care coordinators are implemented as an intervention to facilitate long-term management for CSHCN in order to guide next steps for care coordination within the realm of pediatric TBI. Improved understanding of how care coordination has been found efficacious for the broader population of CSHCN may aid in development of a standard of care for pediatric TBI, better communication among healthcare and community workers, and improved outcomes during recovery from pediatric TBI.

Methods

This scoping review follows the PRISMA framework and methodology for scoping reviews (PRISMA-ScR)²⁴ and is informed by scoping review methodology recommendations by Arksey and O'Malley²⁵ and Levac, Colquhoun, and O'Brien.²⁶ See Supplementary Material for the completed PRISMA-ScR checklist. The methods for this paper match those described more fully in the associated paper²⁷ and are described here briefly.

Data Sources and Search Strategy

In January 2020, an iterative strategy amongst brain injury professionals and a medical librarian generated project search terms. The search incorporated the following databases: OVID/Medline, CINAHL, PsycINFO, EMBASE, and ERIC. The search included the following research components and search terms, listed in parentheses, and combined with AND/OR: 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) Combination of #1 and #2. Following the search, titles and abstracts were exported into Rayyan QCRI,²⁸ a web-based program for systematic reviews.

Screening, Eligibility, and Data Extraction

In the first stage of review, each title/abstract was examined by 2 assessors to determine if an article should move forward to the next stage of review. The second author resolved any disagreements. Two assessors completed full-text reviews to come to consensus for inclusion in the next round of screening, with a third reviewer assisting in cases of disagreement. As this scoping review is an iterative process, during the later stages of this project, articles were also excluded if they ultimately did not fit the evolving inclusion criteria.

Articles were included if they met the following criteria: they were empirical studies that included an examination of at least one intervention related to care coordination for CSHCN, defined for purposes of this review as persons under 25 years of age because some services (e.g., special education) can extend past the age of 18 for persons with special needs. Papers were excluded if they were expert opinion, book chapters, dissertations, or conference abstracts. Articles not written in English, published prior to 2009, or involving a care coordination intervention that would not be relevant to children with TBI were also excluded.

During the full-text review of articles, researchers used a data extraction spreadsheet created for this project to record all relevant variables from each included study (see

Supplemental Material). Each paper was abstracted by 1 of the 4 authors, and 20% of the articles were reviewed by a second researcher to ensure reliability in the data extraction process. 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. As researchers reviewed and discussed the included papers, 3 primary groups of care coordination intervention studies were identified: 1) care coordinator personnel, 2) care coordination tools, and 3) hospital-to-school care coordination for CSHCN. To reflect the natural division present in the literature, we divided our scoping review into 3 distinct manuscripts. Included in this scoping review are the articles focused on outcomes in CSHCN after implementation of care coordination interventions by individuals, dyads, or teams.

Results

Thirty-one articles met the inclusion criteria for this portion of the scoping review focusing on outcomes for CSHCN following implementation of care coordinator interventions. As the studies in this review were read and synthesized, reported outcomes were noted to relate to 5 major categories including: healthcare utilization measures, cost of care, disease status, parent and child quality of life, and healthcare satisfaction and perception of care. Therefore, results were grouped into these 5 categories for comparison of related outcomes between studies. Full-text articles were read and coded based on general study characteristics, type of care coordination intervention, profession(s) of the care coordinator(s), and outcomes. Table 1 denotes general study characteristics of the 31 articles included in this portion of our

scoping review, and Table 2 describes specific care coordination interventions, personnel roles, and outcomes for CSHCN.

All articles were published between 2009-2019 and included studies from the United States and Puerto Rico (n = 22), Canada (n = 3), Australia (n = 2), Italy (n = 1), Japan (n = 1), Switzerland (n = 1), and the United Kingdom (n = 1). Twenty-five of these articles were quantitative studies, 2 were qualitative studies, and 4 utilized mixed methods. As per the inclusion criteria for the overarching scoping review, children and youth in these studies were between the ages of 0-25 years old and had classification as CSHCN or at least one chronic diagnosis. All studies included in this scoping review implemented programs involving care coordination personnel in teams, dyads, or as individuals.

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Table 1. General study characteristics of 31 papers included in this scoping review.

Study	Country of Origin	Sample Characteristics	Diagnoses	Type of Study
Bell et al. (2010)	UK	0-2.5 years old (n=145)	Developmental delay; identified disabilities	Quantitative
Breen et al. (2018)	Australia	0-19 years old (n=534); high use of hospital services	Medical complexity	Quantitative
Britto et al. (2014)	US	13-22 years old (n=58); well-controlled asthma	Asthma	Quantitative
Caskey et al. (2019)	US	0-25 years old (n=6259); Medicaid insurance	Asthma, diabetes, prematurity, seizure disorder, or sickle cell disease	Quantitative
Cohen et al. (2012)	Canada	Mean age of 5.8 years old (n=81); requirement for high intensity care and/or technology assistance	Special health care needs	Mixed
Connor et al. (2018)	US	Sample age not specified (n=565)	Cardiac conditions	Quantitative
Farmer et al. (2011)	US	0-17 years old (n=61); low socioeconomic status; enrollment in Medicaid	Chronic illness	Quantitative
Gans et al. (2015)	US	Parents of children 0-20 years old (n=93)	"Life-limiting conditions"; palliative care	Quantitative
Gans et al. (2016)	US	0-20 years old (n=132)	"Life-limiting conditions"; palliative care	Quantitative
Graham et al. (2017)	US	Median age of 6 years old (n=320); respiratory technology dependence	Chronic respiratory failure	Quantitative

Graham et al. (2018)	US	Median age of 6 years old (n=346); respiratory technology dependence	Chronic respiratory failure	Quantitative
Hamilton et al. (2013)	US	Children 1.6-13.6 years old and their families (n=22); multiple serious chronic illnesses	Special health care needs	Quantitative
Howard et al. (2017)	US	0-25 years old (n=183); post-intensive care; Medicaid insurance	Cerebral palsy	Quantitative
Iqbal et al. (2016)	US	Mean age of 6.2 years old (n=50); English speaking	Asthma with no existing comorbidities	Quantitative
Janevic et al. (2016)	US & Puerto Rico	0-18 years old (n=805)	Asthma	Quantitative
Janevic et al. (2017)	US & Puerto Rico	0-18 years old (n=805)	Asthma	Quantitative
Johaningsmeir et al. (2015)	US	Families of children with a mean age of 3.8 years old (n=54)	Special healthcare needs	Quantitative
Kingsnorth et al. (2013)	Canada	Mean age of 7.5 years old (n=23)	Medical complexity	Qualitative
Kuo et al. (2013)	US	Families of children with ages not specified (n=120); 2+ chronic conditions; 2+ pediatric subspecialists	Medical complexity	Quantitative
Kuo et al. (2016)	US	Families of children with a mean age of 6.9 years old (n=441)	Medical complexity	Quantitative
Peter et al. (2011)	Australia	0-18 years old (n=101)	Medical complexity	Quantitative
Petitgout et al. (2018)	US	0-21 years old (n=158); receiving a tracheostomy	Special health care needs	Quantitative
Seliner et al. (2017)	Switzerland	Parents of children 1-18 years old (n=28); German or English-speaking	Intellectual and/or motor disability receiving hip-joint surgery	Qualitative
Suzuki et al. (2017)	Japan	Families of children 0-17 years old (n=246)	Children with technology dependence for care	Quantitative

Taylor et al. (2012)	US	0-23 years old (n=91); receiving care through 3+ providers	Special health care needs	Mixed
Weier et al. (2017)	US	1-21 years old (n=733); Medicaid insurance	Special health care needs	Quantitative
Weiss et al. (2019)	US	Sample age not provided (n=442); Medicaid insurance	Special health care needs with "high risk diagnosis"	Quantitative
White et al. (2017)	US	Sample age not provided (n=10)	Medical complexity	Mixed
Wittmeier et al. (2016)	Canada	Professionals (n=9) working with children of unreported ages	Medical complexity	Mixed
Wood et al. (2009)	US	0-12+ years old (n=144)	Special health care needs	Quantitative
Zanello et al. (2017)	Italy	Pediatricians (n=40); children of unreported ages (n=49)	Special health care needs	Quantitative

Table 2. Descriptions of specific care coordination interventions, personnel roles, and outcomes for CSHCN for studies included in this review.

Study	Care Coordination Interventions	Individual/Team/Dyad & Profession of Care Coordinator(s)	Outcome Categorization	Results
Bell et al. (2010)	An Early Intervention Team adopted a transdisciplinary approach to deliver family-centered and joint-therapy focused care.	Care coordination team: <ul style="list-style-type: none"> • Therapists • Specialist health visitor • Specialist nursery nurse • Pediatrician • Clinical psychologist • Nurse counselor 	<ul style="list-style-type: none"> • Healthcare utilization 	<ul style="list-style-type: none"> • Attendance and caseloads increased while wait times for high-priority children decreased
Breen et al. (2018)	Care coordinators in the Kids GPS Care Coordination Program in tertiary networks functioned to unite treatment teams, community health services, and families to understand each group's goals and develop a shared-care plan for CSHCN.	Individual care coordinator (no additional information provided)	<ul style="list-style-type: none"> • Healthcare utilization • Cost of care 	<ul style="list-style-type: none"> • Significant decrease in ED visits and day-only hospital admissions • Significant reductions in cost of care • 69% of children without a general practitioner were referred to one

Britto et al. (2014)	A care coordinator was hired to work alongside clinic staff to organize patient data tracking, family and community outreach, scheduling, pre-appointment reminders, and assist in motivational interviewing and behavior change counseling to coach patients in forming personal action plans.	Individual care coordinator (parent of a child with chronic disease)	<ul style="list-style-type: none"> Healthcare utilization Disease status Healthcare perception and satisfaction 	<ul style="list-style-type: none"> Increase in patients with optimally controlled asthma Majority of patients who still did not have optimally controlled asthma had an increase in their asthma control score Asthma-related hospitalizations, ED visits, and patient satisfaction remained stable
Caskey et al. (2019)	A randomized sample was assigned to Usual Care or the Coordinated Healthcare for Complex Kids program where they received a broad approach to care coordination including chronic disease management, mental health services, identification of social determinants of health, and caregiver wellness. Care coordinators specifically assessed family needs and tracked previous healthcare utilization.	Care coordination team: Community health worker as main coordinator plus families were supported via community engagement, technology & data, mental health promotion, provider support services, and legal services	<ul style="list-style-type: none"> Healthcare utilization Cost of care 	<ul style="list-style-type: none"> No significant difference in Medicaid expenses or hospitalizations between groups
Cohen et al. (2012)	A tertiary NP working in conjunction with local pediatricians focused on care coordination, complex symptom management, and patient goal setting during weekly clinics. The	Individual care coordinator (pediatric NP with skills to care for children with medical complexity)	<ul style="list-style-type: none"> Cost of care Parent and child QoL 	<ul style="list-style-type: none"> Decrease in total healthcare costs per patient per month due to fewer inpatient days in a tertiary center Decrease in parent-reported out-of-pocket costs

	NP developed care plans in collaboration with families, used electronic health networks, and accessed hospitalists for additional consultation.			<ul style="list-style-type: none"> • Increase in child QoL in both social and emotional domains • No significant change in parent QoL
Connor et al. (2018)	Care coordination through phone interactions and daily cardiology clinic tasks was handled primarily by RNs, unless outside their scope of practice when completed by APNs and PAs.	Individual care coordinator (RN, APN, PA, or administrative assistant in collaboration with the cardiologist)	<ul style="list-style-type: none"> • Healthcare utilization • Cost of care 	<ul style="list-style-type: none"> • 68.6% of interactions were coordinated by an RN with 53% focusing on management of disease • In 47% of care coordination interactions, adverse outcomes were prevented, including ED visits and medical errors • Significant decrease in estimated cost of care
Farmer et al. (2011)	A family support specialist served as a consultant to care teams in primary care practices by facilitating communication between services and providing individualized services to families like home visits, care plans, and monthly check-ins.	Care coordination dyad: <ul style="list-style-type: none"> • PCP • Family support specialist (nurse, NP, or social worker) 	<ul style="list-style-type: none"> • Healthcare utilization • Disease status • Parent and child QoL • Healthcare perception and satisfaction 	<ul style="list-style-type: none"> • Family-reported improvements in satisfaction with services and decreased need for information • Improved child health ratings, unmet needs, and familial strain
Gans et al. (2015)	The Partners for Children program provided care coordination through a care coordinator evaluating the Family-Centered Action Plan every 60 days to ensure goals were met and often accompanied caregivers to physician visits and IEP	Individual care coordinator (nurse or social worker)	<ul style="list-style-type: none"> • Parent and child QoL 	<ul style="list-style-type: none"> • Significant quantitative decrease in family worry and stress over time • Qualitative decrease in stress and worry from "most of the time" to "sometimes"

	conferences. Education, counseling, and 24/7 on call nursing were also offered.			
Gans et al. (2016)	The Partners for Children program provided care coordination through a care coordinator evaluating the Family-Centered Action Plan every 60 days to ensure goals were met and often accompanied caregivers to physician visits and IEP conferences. Education, counseling, and 24/7 on call nursing were also offered.	Individual care coordinator (nurse or social worker)	<ul style="list-style-type: none"> Healthcare utilization Cost of care 	<ul style="list-style-type: none"> Decrease in healthcare costs mainly due to reduction of inpatient costs Decrease in average length of hospitalization from 16.7 days to 6.5 days
Graham et al. (2017)	The hospital-based Critical Care, Anesthesia, and Perioperative Extension program consisted of a care coordination team who provided home care services and coordination between acute care, primary care, rehabilitation services, schools, and community services. They were available 24/7 with services "on demand" at family request.	Care coordination team: <ul style="list-style-type: none"> ICU physician Full-time respiratory therapist NP Social worker Program administrator 	<ul style="list-style-type: none"> Healthcare perception and satisfaction 	<ul style="list-style-type: none"> High severity patients had more healthcare encounters than low severity patients in a 3 year period High parent-reported satisfaction with program Parents felt that the team understood the child's and family's daily lives
Graham et al. (2018)	The hospital-based Critical Care, Anesthesia, and Perioperative Extension program consisted of a care coordination team who provided home care services and coordination between acute care,	Care coordination team: <ul style="list-style-type: none"> ICU physician Full-time respiratory therapist 	<ul style="list-style-type: none"> Healthcare utilization Cost of care 	<ul style="list-style-type: none"> Prevention of 556 ED visits and 107 hospitalizations over 4 years Decrease in cost of care due to prevention of ED visits and

	primary care, rehabilitation services, schools, and community services. They were available 24/7 with services "on demand" at family request.	<ul style="list-style-type: none"> • NP • Social worker • Program administrator 		hospitalizations and reduced length of stay
Hamilton et al. (2013)	The Pediatric Medical Home Program implemented a primary care model focusing on intensive care coordination. A part-time pediatrician was responsible for care plan development and management, and a full-time bilingual family liaison was responsible for first-line care coordination, cultural barriers, appointment scheduling, parent questions, insurance authorizations, and community-based interventions.	<p>Care coordination team:</p> <ul style="list-style-type: none"> • Bilingual family liaison without a medical background • Part-time pediatrician • Residents • Social workers • Others 	<ul style="list-style-type: none"> • Healthcare utilization • Healthcare perception and satisfaction 	<ul style="list-style-type: none"> • Highest family ratings were reported in "family centeredness" and understanding the child's conditions and goals • Lowest family ratings related to care plans • No statistical difference was noted between English versus Spanish speaking families, but a positive trend was noted in communication rated by Spanish-speaking families
Howard et al. (2017)	The Care Beyond the Bedside model was implemented with children beginning reintegration into life post-intensive care. The care team prepared families for a PCMH with a primary pediatrician or pediatric NP coordinating care with other healthcare professionals.	<p>Care coordination team:</p> <ul style="list-style-type: none"> • Primary pediatrician or pediatric NP • Other healthcare professionals 	<ul style="list-style-type: none"> • Healthcare utilization • Cost of care 	<ul style="list-style-type: none"> • Significant reduction in Medicaid costs per member per month due to fewer hospital readmissions and fewer total inpatient days

Iqbal et al. (2016)	Implementation of a care coordinator for post-clinic visits functioned to schedule timely follow-ups, deliver reminder calls prior to scheduled visits, address barriers, and send the care plan to each patient's PCP after each visit.	Individual care coordinator (no additional information provided)	<ul style="list-style-type: none"> Healthcare utilization Disease status 	<ul style="list-style-type: none"> Significant increase in families that used PCPs as their child's primary asthma provider Parent-reported improvement in child symptoms and greater usage of inhaled corticosteroids and an asthma action plan
Janevic et al. (2016)	An asthma care coordinator provided families with asthma education, an action plan, links to providers, and trigger remediation materials. Typically 1 or more home visits and assessment of social barriers occurred.	Individual care coordinator (RN, community health workers, or health educators)	<ul style="list-style-type: none"> Healthcare utilization Disease status 	<ul style="list-style-type: none"> Marked improvement in child daytime and nighttime symptoms Decreased report of asthma-related ED visits
Janevic et al. (2017)	An asthma care coordinator provided families with asthma education, an action plan, links to providers, and trigger remediation materials. Typically 1 or more home visits and assessment of social barriers occurred.	Individual care coordinator (RN, community health workers, or health educators)	<ul style="list-style-type: none"> Healthcare perception and satisfaction 	<ul style="list-style-type: none"> Significant improvement in parent-reported access to asthma care, confidence in managing their child's asthma, communication with and between providers, and satisfaction with providers
Johaningsmeir et al. (2015)	The Special Needs Program consisted of a nurse care coordinator as the single point of contact who advocated for families at specialty appointments, accessed needed services, facilitated provider communication, and was available 24/7.	Individual care coordinator (nurse)	<ul style="list-style-type: none"> Healthcare utilization Cost of care Parent and child QoL 	<ul style="list-style-type: none"> No significant improvement in QoL measures related to family impact and healthcare satisfaction Shift in tertiary center resource use from inpatient to outpatient Reduction in hospital payments

Kingsnorth et al. (2013)	A care coordination dyad collaborated in the Integrated Complex Care Model as the single point of entry into acute, rehabilitative, and community-based care settings and ensured interprofessional communication along with care plan utilization.	<p>Care coordination dyad:</p> <ul style="list-style-type: none"> • NP or case manager associated with community-based healthcare • NP or case manager associated with acute and/or rehabilitative care 	<ul style="list-style-type: none"> • Healthcare utilization • Parent and child QoL • Healthcare perception and satisfaction 	<ul style="list-style-type: none"> • 75% of families felt care plans were helpful • Over half of parents reported decreased parental burden and improved communication • 42% of parents felt they took on the primary care coordination role • Only 58% of families received a physical copy of the care plan • Two-thirds of care plans contained incorrect care coordinator contact information
Kuo et al. (2013)	The Medical Home Clinic for Special Needs Children employs an outpatient care coordination team with a single assigned nurse coordinator for acute issues or questions.	<p>Care coordinator team:</p> <ul style="list-style-type: none"> • Nurse coordinator • Pediatricians • Nutritionists • Speech therapists • Social workers • Psychologists 	<ul style="list-style-type: none"> • Parent and child QoL • Healthcare perception and satisfaction 	<ul style="list-style-type: none"> • Significant family-reported decrease in needing help with care coordination and increase in receipt of written care plan • Improvements in family-reported satisfaction with choice of doctors/nurses and primary care received • 94% of parents felt like a partner in their child's care • No change reported in meeting children/families' emotional needs or receiving information for family support • Limited impact on parent-reported family functioning

Kuo et al. (2016)	Care coordination was provided through multiple tertiary center-based comprehensive care programs containing an assigned care coordinator that worked with multidisciplinary teams. Services included patient education, care plan development, and support to the child's PCP.	Care coordinator team: <ul style="list-style-type: none"> • Primary coordinator (background not provided) • Health care professionals 	<ul style="list-style-type: none"> • Healthcare utilization 	<ul style="list-style-type: none"> • 55.4% of children used their PCP as the main contact for disease management • Significant decrease in unmet needs in all 14 measured areas, with the greatest decrease in dental care, therapies, mental health, and respite care • 82.9% of families reported all needs met after program enrollment
Peter et al. (2011)	The Ambulatory Care Coordination program provided 24/7 nurse-led care coordination through telephone support, acute care management, development of integrated healthcare plans, communication between providers, and discharge planning.	Individual care coordinator (nurse)	<ul style="list-style-type: none"> • Healthcare utilization • Cost of care • Healthcare perception and satisfaction 	<ul style="list-style-type: none"> • Significant reductions in ED visits, inpatient admissions, and total inpatient days resulting in decreased cost of care • High parent-reported satisfaction with 24/7 telephone support
Petitgout et al. (2018)	The Continuity of Care team focused on care coordination within the hospital and community through interdisciplinary care that was family-centered, continuous among providers, avoided duplication of services, and assisted in accessing medical services or resources.	Care coordination team: <ul style="list-style-type: none"> • Social workers • Nurse clinicians • NP • Continuity of Care Coordinator 	<ul style="list-style-type: none"> • Healthcare utilization • Cost of care 	<ul style="list-style-type: none"> • Decrease in mean length of stay and total hospital charges for enrolled patients • No significant difference in readmission rates between groups
Seliner et al. (2017)	An APN led a family-centered, pre-surgery care intervention providing families with printed information, telehealth counseling, and support before hospitalization. Then, APNs	Individual care coordinator (APN)	<ul style="list-style-type: none"> • Healthcare perception and satisfaction 	<ul style="list-style-type: none"> • Lower family-reported satisfaction with family centered care in intervention group in all domains except "General Information" where a

	provided multidisciplinary team support and at least 1 in-person interaction with the family during the inpatient period.			<p>small intervention effect was found</p> <ul style="list-style-type: none"> • Parents reported wanting to be an equal part of the team and expected coordinated information they did not receive • Improvement in parent-reported pre-surgery preparedness
Suzuki et al. (2017)	Home-visiting nurses coordinated care for children, assessed family functioning, accessed needed services, and tried to decrease parental burden.	Individual care coordinator (nurse)	<ul style="list-style-type: none"> • Parent and child QoL 	<ul style="list-style-type: none"> • No significant difference in parental burden found between groups • Increased nurse care coordination predicted decreased caregiver-related burden for parents, physical strain, and social restrictions
Taylor et al. (2012)	Comparison between implementation of Care Binders containing information important for tracking and planning care versus the Care Coordinator Counselor role as a resource for providers and families to navigate the healthcare system. This role mainly focused on family coaching, evaluation of care needs, and coordination of services.	Individual care coordinator (Bachelor's degree in nursing plus 5 years' experience in a complex medical environment)	<ul style="list-style-type: none"> • Healthcare utilization 	<ul style="list-style-type: none"> • Significant difference between groups on care coordination composite measures, with the intervention group receiving more positive responses • 75% of patients graduated their Counselor, as they found another coordinator and felt comfortable navigating the healthcare system themselves

Weier et al. (2017)	The Partners for Kids program implemented care coordinators that worked with families to create care plans and individualize goals. They contacted families at least once per month, had a team member visit every 90 days, updated the care plan quarterly, and identified community providers.	Care coordination team: <ul style="list-style-type: none"> • Nurse or social worker as lead • Non-licensed staff as support 	<ul style="list-style-type: none"> • Healthcare utilization 	<ul style="list-style-type: none"> • Statistically significant decrease in the number of inpatient admissions and inpatient bed days
Weiss et al. (2019)	A Patient Care Coordinator was used to obtain records, complete screening tools, schedule appointments, develop care plans, and act as the primary contact point for care. They scheduled Interdisciplinary Care Team meetings between the patient and multiple professionals and sent information to the patient's PCP.	Individual care coordinator (nurse)	<ul style="list-style-type: none"> • Healthcare utilization • Cost of care 	<ul style="list-style-type: none"> • Significant reduction in ED visits, inpatient admissions, and inpatient length of stay • Medical cost savings were 3 times that of program costs
White et al. (2017)	A core team for inpatient hospital medicine with stable and rotating members was developed for care coordination rounds, medical reconciliation rounds, and multidisciplinary team participation in handoff to outpatient providers.	Care coordination team: <ul style="list-style-type: none"> • Nursing unit • Hospital medicine attending • Senior resident, interns • Medical students • APRNs • Pharmacist • Dietician 	<ul style="list-style-type: none"> • Healthcare perception and satisfaction 	<ul style="list-style-type: none"> • Attending physicians and APRNs felt the team was more rewarding and made complex care easier but felt service blocks were "emotionally exhausting" • Residents reported the team to be integral for care coordination but had challenges with access to staff and the emotional toll • Nurses reported overall positive reviews

		<ul style="list-style-type: none"> • Social worker 		<ul style="list-style-type: none"> • Families reported positive feedback in all areas, especially communication and collaboration
Wittmeier et al. (2016)	Case studies of implementation of a central intake coordinator in physiotherapy allowed for tailoring of rehabilitation services to individual needs and coordination of outpatient referrals.	Individual care coordinator (no additional information provided)	<ul style="list-style-type: none"> • Healthcare utilization • Healthcare perception and satisfaction 	<ul style="list-style-type: none"> • All participants reported positive outcomes with major changes in reduced service duplication, equitable wait times, greater interprofessional communication, and easier access of services. • For children with neurodevelopmental needs in high priority, wait times significantly decreased.
Wood et al. (2009)	Comparison of practice-based nurse care coordinators where the nurse is onsite at the pediatric primary care office and conducts monthly practice-based assessment meetings versus agency-based nurse care coordinators where the nurse is located offsite and does not hold practice-based meetings.	Individual care coordinator (nurse)	<ul style="list-style-type: none"> • Healthcare utilization • Healthcare perception and satisfaction 	<ul style="list-style-type: none"> • Family-reported satisfaction improved for both groups but more so for the practice-based group • Fewer barriers were reported among both groups, with better ratings for the practice-based group • The practice-based group reported higher satisfaction, more support, and greater referral to outside resources
Zanello et al. (2017)	Implementation of PCPs as the main care coordinator for children in the Special Needs Kids program to improve hospital discharge, integration of social and hospital	Individual care coordinator (PCP)	<ul style="list-style-type: none"> • Healthcare utilization 	<ul style="list-style-type: none"> • 80% of records reported care coordination prevented inappropriate service use, mainly due to increased specialty referral.

	services, and transition to outpatient care.			
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***Abbreviations:** ED= emergency department; NP= nurse practitioner; QoL= quality of life; RN= registered nurse; APN= advanced practice nurse; PA= physician's assistant; PCP= primary care physician; IEP= individualized education plan; ICU= intensive care unit

Healthcare Utilization Measures

Twenty-three studies implementing care coordinators for CSHCN included outcome variables measuring overall healthcare utilization, broadly defined as inpatient and outpatient usage of healthcare services, the types of services received, and obstacles encountered while receiving those services. The 6 major healthcare utilization outcomes described in these 23 studies include: (1) inpatient length of stay, (2) emergency department visits, hospitalizations, and readmissions, (3) use of outpatient treatment and prevention of inappropriate services, (4) access, barriers, and wait time to care, (5) unmet needs, and (6) care plan creation and utilization.

Inpatient Length of Stay. Six studies examined inpatient length of stay. All 6 studies found that implementation of care coordinators decreased the total number of inpatient days for CSHCN.^{29–34} Data from Gans et al.²⁹ revealed average inpatient length of stay was reduced by 10.2 days, demonstrating a reduction from over 2 weeks to less than 7 days after care coordination interventions were applied.

Emergency Department Visits, Hospitalizations, and Readmissions. Of the papers measuring the frequency of medical encounters after implementing care coordination personnel for CSHCN, studies reported data on emergency department visits, hospitalizations/inpatient admissions, and readmission rates. Six of the 7 studies examining trips to the emergency department showed a statistically significant decrease in the number of disease-related visits after the implementation of care coordination,^{30,31,35–38} while Britto et al.³⁹ found no change in rate of emergency department visits after implementing an individual care coordinator. Five of 7 studies measuring hospitalizations/inpatient admissions after

implementing a care coordinator demonstrated a significant decrease in total admissions.^{30,31,34,35,38} Studies by Caskey,⁴⁰ Britto,³⁹ and colleagues found no significant decrease in hospitalizations after implementing a care coordinator intervention. Of the 2 studies examining readmission rates, Howard et al.³² found that care coordinators were associated with a reduction in readmission rates, but Petitgout et al.³³ found no significant change. Amongst all these studies, Graham et al.³⁸ found that care coordinator implementation was associated with a reduction of 556 emergency department encounters over 4 years, and Breen et al.³⁵ found that 557 total hospital encounters were prevented over 6 months following implementation of a care coordination team.

Use of Outpatient Treatment and Prevention of Inappropriate Services. After implementation of care coordinator personnel, 5 papers reported on the shift to increasing usage of outpatient over inpatient services, and 3 papers found that the implementation of care coordinators reduced the use of inappropriate healthcare services for CSHCN. When families of CSHCN had access to a care coordinator, studies found increased use of outpatient care services⁴¹ and a shift toward primary care pediatricians compared to specialists or inpatient services.^{35,42,43} These studies also found an increase in the number of referrals to outside resources including community services⁴⁴ and a decrease in families accessing inappropriate, unnecessary, or duplicated medical services.^{36,45,46}

Access, Barriers, and Wait Time to Care. Several papers included in this scoping review explored the effect care coordinators had on CSHCN and their families' ability to access appropriate medical care. Janevic,⁴⁷ Wittmeier,⁴⁵ and colleagues found that families of CSHCN reported an increase in ease of access to healthcare services once they were connected with

care coordinators who streamlined the process of scheduling and simplified families' ability to directly communicate with providers. Wood et al.⁴⁴ measured barriers to care by asking families to rate 17 services on the degree of obstacles encountered when trying to access that service. With an individual care coordinator in the primary care setting, barriers decreased, allowing for greater access to services. Bell et al.⁴⁸ found that overall wait time for outpatient care decreased with utilization of a care coordination team. They noted a decrease in wait times for high-priority children despite an increase in caseloads, allowing for more patients to be seen by a provider in less time.

Unmet Needs. Two included studies examined changes in amounts of self-reported unmet needs for children and their families after implementation of a care coordinator intervention. Farmer et al.⁴⁹ and Kuo et al.⁴³ found a decrease in the number of unmet needs for children and their families, with Kuo et al.⁴³ specifically reporting a decrease in self-reported unmet needs in 14 specialty areas, with the largest decreases in unmet needs occurring in dental care, therapy, mental health, and respite care.

Care Plan Creation and Utilization. Seventeen articles described how care coordination completed by either an individual care coordinator or members of a care coordination team impacted care plan creation and utilization.^{29–31,34,35,37,39,42,43,47,49–55} Yet, only 6 of the 17 papers directly reported outcomes on family usage and satisfaction with the developed care plans. Parents were found to show increased awareness of care plans for their child⁵⁴ and self-reported an increase in using the care plan to help determine their child's needs.^{42,49} However, in one study, questionnaire satisfaction ratings related to care plans were the lowest scoring items.⁵² Kingsnorth et al.⁵³ found that although 75% of families reported care plans to be

helpful, 58% of families never received physical copies of their child's care plan, and approximately 66% of care plans contained incorrect information. Taylor et al.⁵⁵ reported a 28% rise in parent satisfaction with care when they were connected to a care coordinator and received a care binder that included their child's care plan and other important information compared to those parents who received the binder only.

Cost of Care

Ten of 11 papers studying the cost of care for CSHCN demonstrated an overall decrease in the cost of care after the implementation of individual or team care coordinators.^{29–33,35,36,38,41,50} Out-of-pocket costs also decreased.⁵⁰ In balancing the cost of implementation of care coordination programs, Graham et al.³⁸ found the net cost of care savings was approximately \$407 per child per month. Only Caskey et al.⁴⁰ found no significant difference in costs between usual care (no care coordinator) versus the “Coordinated Healthcare for Complex Kids” program, which included care coordination teams with individuals from multiple disciplines and a designated community health worker as the initial director.

Disease Status

Four studies examined the effect of care coordination on disease status and change in severity of symptoms.^{37,39,42,49} Farmer et al.⁴⁹ reported that parents rated their child's health more positively when care coordinators were involved. Other studies reported that following implementation of care coordinators for CSHCN, disease symptoms decreased,^{37,42} with 1 study achieving optimal control in 10% of patients and increased control in another 60% of patients.³⁹

Parent and Child Quality of Life

Findings within this category report on the impact of care coordinators on measures of parent and child quality of life (QoL) and the influence on overall family functioning.

Quality of Life Scores and Parent Self-Report of Burden of Care. Four studies reported on parent and child QoL scores and parental burden of care.^{41,50,53,56} One study reported increases in child QoL,⁵⁰ but several reported that care coordinators did not substantially increase parental QoL.^{41,50} Kingsnorth et al.⁵³ found over half of families felt there was less parental burden when they were connected with a care coordinator, while Suzuki et al.⁵⁶ found a decrease in caregiving-related parental burden, physical strain, and social restrictions, but not overall parental burden.

Family Functioning and Stress. Two of 3 studies reported an overall decrease in familial strain and stress when families of CSHCN were connected to a care coordinator.^{49,51} However, after implementation of a care coordination team, Kuo et al.⁵⁴ found limited impact on family-reported functioning and no reported increase in family receipt of information about available support services.

Healthcare Satisfaction and Perception of Care

Studies within this category investigated the impact of care coordinators on overall satisfaction with services received from healthcare providers, perceptions about the delivery of care, and communication with families and among multidisciplinary healthcare teams. Family satisfaction and perceptions about care delivery were reported for both care coordination individuals/teams and associated professionals with whom CSHCN and their families interacted during care coordination activities.

Healthcare Satisfaction. Ten papers measured overall family-reported healthcare satisfaction after the application care coordinator interventions.^{30,39,44,47,49,52,54,57–59} Eight of the 10 papers found that families reported an increase in overall healthcare satisfaction after they were connected to care coordinators.^{30,44,47,49,52,54,58,59} Of the 2 papers that did not find an increase in family satisfaction, Britto et al.³⁹ found patient satisfaction remained the same, and Seliner et al.⁵⁷ found decreased satisfaction ratings in all areas except “general information.”

Perceptions of Care. Nine papers measured family perception of the care they received from care coordinators and other medical professionals. Six of the 9 papers reported generally positive perceptions of overall care, care coordination efforts, and healthcare team members.^{44,47,49,52,54,58} Care coordinators also improved caregivers’ perceptions of their child’s care. For example, 94% of parents who were supported by care coordinators reported that they felt like partners in their child’s care,⁵⁴ and parents reported increased confidence in managing their child’s chronic illness.⁴⁷ Two studies reported negative family perceptions of care coordination. Seliner et al.⁵⁷ found that parents expected information they did not receive and did not feel like an equal part of their child’s team after implementation of a pre-surgery individual care coordinator. Kingsnorth et al.⁵³ found that 42% of parents felt they took on the primary care coordination role for their child even after implementation of a care coordinator dyad in both the community and acute/rehabilitative care settings. Lastly, one article measured healthcare professionals’ perceptions of care coordination efforts after participating in a care coordination team themselves. Results showed most professionals felt complex care was easier and more rewarding in the team setting, but participation was “emotionally exhausting” and frustrating when there was limited access to needed staff.⁵⁹

Patient-Provider and Interprofessional Communication. Each of the 4 papers examining communication as an outcome of care coordinator as an intervention for CSHCN demonstrated that families reported increased patient-provider communication when coordinators were involved in their care.^{45,47,53,59} Wittmeier et al.⁴⁵ also reported an increase in family-perceived interprofessional communication after the implementation of an individual central intake coordinator for physiotherapy services.

Discussion

This scoping review synthesizes the past decade of literature pertaining to the implementation of care coordinators, whether individual or in teams, for CSHCN and their families in 5 major outcome categories: healthcare utilization measures, cost of care, disease status, parent and child quality of life, and healthcare satisfaction and perception of care. Implementation of care coordinators in studies included in this review resulted in overall positive outcomes for CSHCN across all 5 outcome categories. These studies provide insights into how future research and clinical care guidelines might consider the implementation of care coordinators to improve the long-term care of children and adolescents who sustain a TBI.

CSHCN and their families have high rates of healthcare service utilization, as they require complex care from a variety of professionals. One study reported that a sample of CSHCN averaged 20-32 healthcare encounters in a 3-year span with the highest frequency seen in children with more severe conditions.⁵⁸ More healthcare encounters create a complex and rapidly changing patient history with increasing information to be shared amongst a multitude of professionals. Care coordination systems are important for these complex patients to ensure that healthcare information is accurately and efficiently communicated between professionals

and between professionals and families of CSHCN. As many of the studies included in this scoping review illustrate, implementing a care coordinator for CSHCN has the potential to improve communication and the delivery of services for these individuals by standardizing processes and creating a central coordination role for organization of all needed services. Based on the findings from these studies, there are several opportunities to consider in future, prospective care coordination studies for children with TBI.

Overall, studies that examined shifts in healthcare utilization following implementation of care coordinators demonstrated a shift from emergency department and inpatient care to outpatient service usage and a decrease in both unmet needs and inappropriate services accessed. Studies demonstrated that increased continuity of care can be achieved with use of care plans in combination with care coordinators, although further research is warranted regarding optimal care plan composition and usage. Children with TBI often have an increased number of healthcare appointments across a variety of specialty areas including therapy services, mental health services, and respite care. The multitude of appointments required for this population has been shown to be a barrier to attending follow-up appointments due to scheduling conflicts.⁶⁰ Since TBI is a chronic condition that can be unpredictable and continually evolving, children often have unidentified and unmet needs as well. As with other CSHCN, use of a care coordinator for children with TBI has the potential to improve acute and long-term healthcare encounters, access to appropriate care, continuity and efficiency of care, and reduce unmet needs. Future research should examine the effects of care coordination on overall healthcare utilization in children and adolescents with TBI.

Studies that examined cost of care after implementation of a care coordinator demonstrated a significant decrease in cost,^{29–33,35,36,38,41,50} except for 1 study.⁴⁰ Caskey et al.⁴⁰ did not find a decrease in healthcare costs when a care coordinator was implemented, but CSHCN in this study also did not have significant reductions in emergency department visits, hospitalizations, or inpatient days, suggesting that the decrease in cost of care seen in other studies was likely the result of an overall decrease in healthcare utilization, specifically the use of acute care services. This decrease in healthcare costs seen across the majority of studies was maintained when the cost of implementing a care coordination program was considered.³⁸ Therefore, the findings of the studies in this review suggest that implementation of a care coordinator results in reductions in healthcare costs by decreasing usage of acute care services and increasing usage of preventative outpatient care for CSHCN. Similar to other CSHCN, children with TBI have high rates of healthcare utilization, resulting in increased healthcare costs. By increasing use of outpatient services, such as primary care, rehabilitation services, and mental health services, the frequency of acute care service usage has the potential to decrease, which could decrease the overall cost of care for this population. Standardizing care coordination processes using a care coordinator for children with TBI may result in more organized and efficient referrals and care processes to decrease unnecessary service usage.

Studies that examined factors related to disease status based on symptom frequency and child health ratings reported overall improvements when care coordinators were implemented as an intervention for CSHCN. Results from these studies^{37,39,42,49} suggest that care coordinators promote care that better meets the complex and chronic needs of CSHCN. However, studies that examined factors related to disease status only lasted between 6 months

and 1 year. Future research should examine the ability of care coordinators to meet the long-term needs of CSHCN, including children with TBI. As TBI has fairly recently been recognized as a chronic, long-term condition,⁶¹ findings from studies of CSHCN indicate that care coordinators might also be a promising intervention for individuals who experience a TBI during childhood. The younger age at which an individual experiences a TBI, the greater the impact on their long-term function.⁶² Therefore, it is imperative that the population of children with TBI receive adequate care coordination across the lifespan to identify and address needs that emerge throughout all stages of development. Use of a care coordinator may be beneficial in improving the health and symptom frequency of children with TBI, as seen in other CSHCN.

Studies that examined parent and child QoL reported no increase in parent-related QoL, even when child-related QoL improved, and results were inconclusive regarding the impact of a care coordinator on parental burden. However, studies did find an overall decrease in familial strain and stress when families had access to a care coordinator. Because family strain and stress improved but parental QoL did not, other factors aside from the stress of coordinating the care of a CSHCN likely impact parents' well-being. Results from studies examining the effect of a care coordinator on parent and child QoL demonstrate the importance of evaluating parental support and well-being and providing resources for parents of CSHCN, including caregivers of children with TBI. Future studies should examine the inclusion of parental support services in care coordination interventions. A family-centered approach to care has the potential to more holistically address the needs of a CSHCN and their caregivers,^{63–65} including families with children who have a TBI. Family functioning can impact the long-term outcomes for children with TBI, and studies examining QoL and parental burden/stress following the

implementation of care coordinator interventions indicate that this has promise for youth with TBI.⁶⁶

When a care coordinator was involved in their child's care, studies that examined family-reported healthcare satisfaction and perception of care generally found that families were satisfied with healthcare services received,^{30,44,47,49,52,54,58,59} had overall positive perceptions of care,^{44,47,49,52,54,58} and perceived an increase in patient-provider and interprofessional communication.^{45,47,53,59} Choosing care coordinators with qualifications that may specifically address the needs of a certain population of CSHCN may result in better outcomes. For example, the intervention implemented in Hamilton et al.⁵² received high satisfaction ratings in "family centeredness" with a care coordination team focusing on cultural barriers, parent questions, and community-based interventions. In this program, a bilingual care coordinator was utilized to better fit the needs of their target population. Future research should examine the qualifications for care coordinators that will specifically address the needs of a targeted population, such as children with TBI. When implementing care coordination with families of children who have TBI, it may be most beneficial to have care coordinators that are familiar with the medical, educational, social, and mental health needs of children within this population. Only one study examined healthcare professionals' perceptions of care coordinators and found that professionals felt that a care coordination team made complex care easier.⁵⁹ However, being part of a care coordination team created a higher workload, leading to emotional stress and difficulties appropriately accessing staff.⁵⁹ Parents have also reported similar complaints of feeling the burden of care coordination for CSHCN, and it is essential that future research incorporate outcome measures to take this perspective into

consideration. However, both parents and healthcare professionals appeared to perceive care coordinators as beneficial overall, despite the challenges encountered, but future studies should examine ways to balance parents' and professionals' participation in care coordination efforts, without placing undue stress and responsibility on either group. When implementing care coordination with families of children who have TBI, it may be most beneficial to have care coordinators that are familiar with the medical, educational, social and mental health needs of children within this population.

Limitations

This scoping review provides a broad review of the literature pertaining to care coordinator interventions used with CSHCN with a variety of diagnoses. Because the body of research is heterogeneous, conclusive recommendations regarding clinical practice and research cannot be made. As is typical for reviews of this type, it is possible that some relevant articles were not included in our review due to chosen search terms, search strategies, and inclusion criteria. For example, articles published prior to 2009 were not included in this review to allow for synthesis of the most recent literature pertaining to our topic.

Conclusions and Future Directions

Care coordinators for CSHCN can take a variety of forms: individuals, dyads, and teams of different sizes. Results from this scoping review do not indicate that the number of individuals involved in the care coordinator role impact intervention outcomes. Studies identified positive outcomes using a range of care coordinator groupings, and null (or negative) results were not associated with a specific type of care coordinator intervention. Utilization of care coordinators (individual, dyad, or team) for CSHCN generally resulted in positive outcomes in the following

domains: healthcare utilization measures, cost of care, disease status, parent and child quality of life, and healthcare satisfaction and perception of care. However, there are many factors to consider when staffing the care coordinator role(s), such as profession, qualifications, and education levels. Few studies in this review compared care coordinator roles based on these different variables. Therefore, future research should examine factors that should be considered when staffing care coordinator positions for a targeted patient demographic. For example, future research that examines implementation of a care coordinator for children with TBI should examine care coordinator qualifications that will be most relevant to pediatric TBI to foster the best long-term outcomes for these individuals and the most efficient and effective use of the care coordinator to support the family. Medical homes may be an optimal setting to implement a care coordinator for children with TBI, as the 2018 CDC Report to Congress recommends that children with TBI receive care coordination within the setting of a medical home.¹⁴ Additionally, Van Cleave et al.⁶⁷ discuss that medical homes may provide the best outcomes for CSHCN when utilizing a proactive approach to care coordination, rather than a reactive approach that only meets patients' immediate needs. Implementing a care coordinator as an intervention in the medical home may help to provide better preventative care to children and adolescents with TBI and allow improved responses to needs that may change over time. Ultimately, these interventions may help to improve the long-term outcomes of children who sustain a TBI.

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