


Psychosocial support and care for children with special healthcare needs and their families

A scoping review for enhancing the care system

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Abstract

Background: Advances in medical technology have increased the identification of children with special healthcare needs (CSHCN), indicating the need to strengthen care systems. However, existing systematic reviews are outdated, over a decade old, and narrowly focused—primarily on hospital-based comprehensive care programs and family-centered care. This scoping review aimed to organize and integrate existing findings on care and support for CSHCN and their families from the available literature.

Methods: We employed an extensive search in December 2023, utilizing databases such as PubMed, Web of Science, CINAHL, ERIC, and The Cochrane Library. Selected articles were thoroughly reviewed, categorized, and organized by the type of care and support addressed. The findings of the included studies were organized and integrated descriptively.

Results: Following a comprehensive search and screening process, 49 articles were selected and categorized into 5 themes: care systems based on hospitals and other specialized institutions, specialized personnel or programs for care coordination/integrated care, support using telehealth technology to enhance and facilitate care, care aimed at reducing the psychological burden on the child and family, and peer and group support emphasizing the role of family and community. Publication years ranged from 1998 to 2023. The studies were conducted in 7 countries, predominantly in the United States, with additional studies from Canada, Australia, the United Kingdom, Japan, India, and Belgium.

Conclusions: This study underscores the importance of establishing effective care systems that ensure continuous and smooth care coordination from multiple perspectives for the well-being of CSHCN and their families. To enhance support systems for the well-being of CSHCN and their families, it is necessary to pursue a multi-faceted approach that facilitates continuous and smooth care coordination from various perspectives.

Abbreviation: CSHCN = children with special healthcare needs.

Keywords: child health, chronic disease, delivery of healthcare, disabled children, scoping review

1. Introduction

Children with special healthcare needs (CSHCN) are defined as “children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”^[1] Previous studies

have reported diseases and disorders such as asthma, diabetes, allergies, visual impairment, epilepsy, and neurodevelopmental disorders such as attention-deficit hyperactivity disorder and developmental delays among CSHCN.^[2]

Advancements in healthcare and medical technology have significantly increased the number of children living with these chronic conditions and disabilities.^[3] However, caring for

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Ethical approval for this study was obtained from the Nagoya City University Graduate School of Nursing Research Ethics Committee (Approval number/22003-3).

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CSHCN entails significant time commitments, complex scheduling, coordination with diverse healthcare providers, and direct care for the children.^[3] Furthermore, families of CSHCN often encounter psychological and financial challenges while assuming the responsibility of providing care for their children at home.^[4,5] Research indicates that the burden associated with caring for CSHCN is associated with a lower quality of life for the family.^[6]

These findings emphasize the need for comprehensive care for CSHCN as well as their families.^[4–6] Nevertheless, the existence of unmet care needs for CSHCN and their families suggests the requirement for further enhancements in the care system.^[7,8] Specifically, typical unmet needs include access to specialized care and community support, with an emphasis on the importance of improved care coordination and systems to support and protect children.^[7–9]

To develop a comprehensive care system that contributes to the well-being of CSHCN and their families and effectively addresses their unmet needs, a thorough review of prior findings on care and support practices is crucial. Thus, it is essential to integrate findings from multidisciplinary and multifaceted practices related to children's care, healthcare systems, and family support.

In recent years, diverse knowledge has emerged regarding care and support related to CSHCN.^[10] While some studies have reported that CSHCN requires integrated, coordinated, and actively co-managed care involving multiple professions, others have reported the efficacy of hospital-based programs in streamlining care.^[10,11]

Despite this knowledge, few systematic reviews have addressed these accumulating findings, and those that exist are over a decade old and narrowly focused, primarily on hospital-based comprehensive care programs and family-centered care.^[12,13] These previous reviews have failed to delineate definitive systems or optimal care models that are suitable for leading care for CSHCN, leaving considerations regarding the exact components of family care for future research.^[12,13] Therefore, an updated review that integrates findings from various perspectives, including family care considerations, and that avoids limiting the institution or profession leading the care would help enhance the care and support for CSHCN and their families.

To address these knowledge gaps, we conducted a scoping review aimed at organizing and integrating existing findings on care and support for CSHCN and their families from available articles. This review offers a broad synthesis of research findings, regardless of research methods or sample size, to provide comprehensive insights into the current status of care and support for CSHCN and their families.

2. Methods

2.1. Study design

A scoping review was employed as a method to organize and integrate findings on care and support for CSHCN and their families, regardless of research methodology. This method is appropriate when the purpose of the review is to identify gaps in knowledge, scope a body of literature, and clarify concepts.^[14]

We conducted the review using Arksey and O'Malley Methodological Framework for Scoping Reviews,^[15] and our work complies with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for the Scoping Reviews) checklist.^[16] The protocol of this study has been registered in the Open Science Framework (<https://osf.io/7awre/>).

Ethical approval for this study was obtained from the Nagoya City University Graduate School of Nursing Research Ethics Committee (Approval number/22003-3).

2.2. Search strategy

This review aimed to identify articles addressing care and support for CSHCN and their families. Peer-reviewed articles published in English were included. First, we conducted an article search according to the preestablished protocol and study eligibility criteria, with reference to the results of a preliminary search.

In December 2023, an article search was conducted using the following databases: PubMed, Web of Science, CINAHL, ERIC, and The Cochrane Library (including the Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, and Cochrane Clinical Answers). Search strategies were developed under the guidance of a professional searcher who understood our review objectives. An example of the final search strategy is provided below:

Database: PubMed

Search strategy (LIMIT DATE 1 January 1998 to December 2023):

((cshcn[Title/Abstract]) OR ("children with special needs"[Title/Abstract] OR "children with special health care needs"[Title/Abstract] OR "children with special health care needs"[Title/Abstract]) OR ("children with special need"[Title/Abstract] OR "children with special health care need"[Title/Abstract])) AND (care[Title/Abstract] OR cares[Title/Abstract] OR "support"[Title/Abstract] OR "service"[Title/Abstract]).

Screening of the articles was conducted independently by 2 researchers (TN and TK), following a calibration exercise using a subset of 100 articles extracted by database screening to enhance consistency. In case of disagreement between the researchers, discussions were held until a consensus was reached.^[16]

2.3. Selection criteria

2.3.1. Inclusion criteria.

1. Articles must have a primary focus on the care and support of CSHCN and their families.
2. Articles must have been published since 1998 when the definition of CSHCN was clarified.^[1]
3. Articles should concern care and support related to living, growth and development, and parenting, rather than the treatment of a specific disease.

2.3.2. Exclusion criteria.

1. Articles that examine only burden or experience without mentioning care and support.
2. Articles with a focus that differs from existing article reviews (i.e., a review of existing screeners for medical student education).
3. Articles related to the development of a CSHCN screener.
4. Articles related to the evaluation of insurance schemes in specific countries.
5. Articles on oral care and dental treatment, as these care systems were deemed dissimilar to the rest of the literature.
6. Articles on disaster preparedness.
7. Articles on adult transition support.
8. Articles on education for internship medical students.
9. Articles providing statistical information only.

2.4. Collating, summarizing, and reporting the results

Each selected article was carefully read, categorized, and organized according to the type of care and support reported. Subsequently, the findings of the included studies were organized and integrated descriptively.

3. Results

3.1. Search results

The number of articles extracted from each database screening is presented in Fig. 1, with a total of 49 articles ultimately selected. The details of the article screening process are also presented in Fig. 1.

3.2. Characteristics of included studies

The details of the 49 selected studies are listed in Table 1. Three-fourths of the selected articles originated from researchers in the United States, with others originating from Canada, Australia, the United Kingdom, Japan, India, and Belgium. The publication years ranged from 1998 to 2023.

Based on the type of care and support that was the focus of the studies, the selected articles were categorized into the

following 5 themes: care systems based on hospitals and other specialized institutions; specialized personnel or programs for care coordination/integrated care; support using telehealth technology to enhance and facilitate care; care focused on reducing the psychological burden on the child and family; peer and group support focusing on the power of the family or community.

3.3. Care systems based on hospitals and other specialized institutions

Approximately half of the 49 studies focused on care coordination and complex care, with 10 articles examining specialized institutions, such as hospitals and medical homes, as the center of care coordination and complex care.^[17–25]

Studies have reported that having care provided by a patient-centered medical home can reduce the time burden of

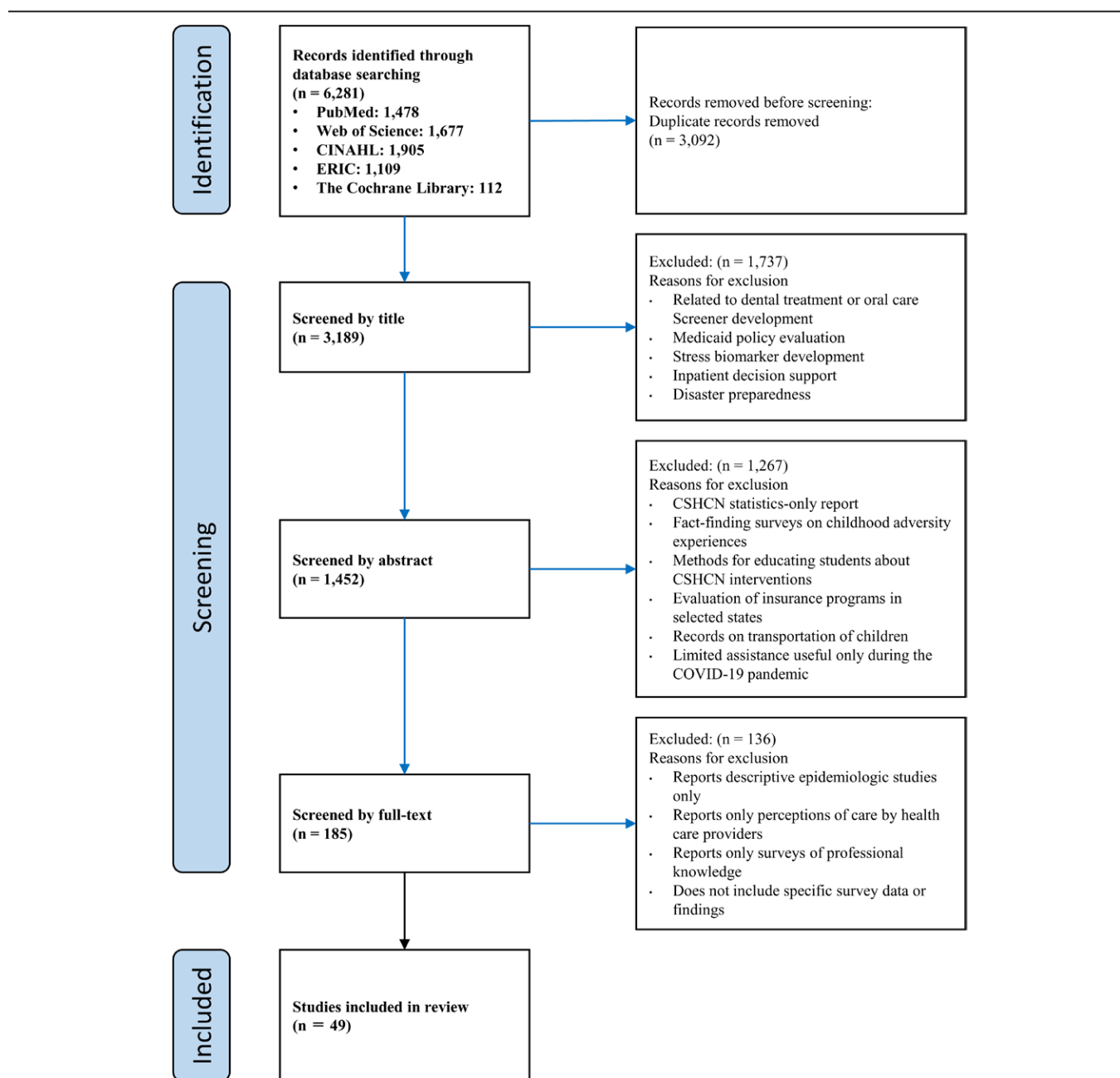


Figure 1. Flow diagram depicting article search and selection. CSHCN = children with special health care needs.

Table 1**Basic characteristics of the included studies in this review.**

Author, year, country	Topics	Intervention/ target group	Data Sources, sample size	Outcomes	Findings
Focused care/support: Care system based on hospitals and other specialized institutions					
Farmer et al., 2011, USA ^[17]	Consultative care coordination through medical home	CSHCN referred by a Medicaid managed care plan	Pre- and post-survey of CSHCN control group (n = 36) and intervention group (n = 25)	Child health services, family functioning, child health and functioning, program acceptability	Enhanced care processes were associated with favorable changes in important long-term outcomes, including assessment of child health status and family functioning.
Farmer et al., 2005, USA ^[18]	Comprehensive primary care interventions	CSHCN in rural areas	Pre- and post-program evaluations of 51 parents with children with special care needs	Child health services, family functioning, child functioning, program acceptability	Primary care providers can use a team approach to improve comprehensive, coordinated care for chronically ill children and their families, even if they live in more rural parts of the country.
Lin et al., 2018, USA ^[19]	Patient-centered medical home	CSHCN under 18 years	CSHCN under age 18 (N = 8802) from national data sources and event data and in-person interviews	Healthcare costs and quality of care indicators	Receiving care from a patient-centered medical home was not associated with overall healthcare costs but was significantly associated with improved parent-reported healthcare quality.
Litt and McCormick, 2015, USA ^[20]	Care coordination delivered in the setting of a family-centered medical home	CSHCN under 18 years	34,459 CSHCN from the 2009–2010 National Survey of Children with Special Health Care Needs	Unmet needs and functional impairment	Care coordination is associated with a lower probability of functional impairment in CSHCN, especially when provided in a family-centered medical home.
Martin et al., 2007, USA ^[21]	A pilot project providing a medical home to CSHCN	CSHCN in rural areas	44 CSHCN and 132 non-CSHCN	Hospitalization, infant/toddler checkups, or preventive visits	It is difficult to draw conclusions about the impact of the presence of a medical home on hospitalization in this study.
Miller et al., 2015, USA ^[22]	Components of medical homes	Families with CSHCN	40,242 CSHCN from the National Survey of Children with Special Health Care Needs population-based study.	Time burden	Family-centered care, care coordination, and obtaining necessary referrals were associated with 15–32% lower odds of time burden to arrange/coordinate care and 16–19% lower odds of providing care.
Petitgout, 2018, USA ^[23]	A hospital-based care coordination program	Pediatric patients with a tracheostomy	Data on a total of 158 patients was extracted electronically from medical records.	Hospitalization costs	Care coordination programs for CSHCN undergoing tracheotomy may be useful in ascertaining whether care coordination programs are effective and result in cost savings.
Petitgout et al., 2013, USA ^[24]	A hospital-based care coordination program	CSHCN from birth through age 21 years	1987 CSHCN who participated in the continuity of care program	Length and cost of hospitalization, caregiver satisfaction	Pediatric nurse practitioners play an important role in the medical home, collaborating with primary care providers, hospital-based specialists, community services, and social workers to serve CSHCN.
Van Cleave et al., 2015, USA ^[25]	Care coordination in primary care	Patients with special health care needs	Care coordination in 12 pediatric practices; interviews with 48 clinicians, care coordinators, and parents and a chart review of 60 patients.	Activities: interviews with families, developing care plans, etc.	In high-performing medical homes, care coordination activities have shifted from being reactive to the spontaneous needs of patients to being more systematic, proactive, and comprehensive.
Focused care/support: Specialized personnel or programs for care coordination/integrated care					
Adams et al., 2013, Canada ^[26]	Comprehensive care plans	Children with medical complexity	Healthcare providers (n = 15) and parents (n = 15) of children with medical complexity who used a comprehensive care plan	Usefulness and desirability of semi-structured interviews and focus groups	Care plans were reported to flatten the hierarchical relationship between healthcare providers and parents, resulting in mutual information exchange and stronger relationships.
Cohen et al., 2012, Canada ^[27]	Community-based complex care clinics integrated with a tertiary care center	Children with medical complexity	Families of 81 children with underlying chronic illnesses, vulnerable, in need of high-intensity care and technical assistance, and with multiple health care providers involved	Socioeconomic status, satisfaction of caregivers, health care utilization	Families experienced long-term cost savings and both families and healthcare providers were highly satisfied.
Costich et al., 2019, USA ^[28]	A community health worker program	Families of CSHCN	Post-project analysis of those who completed the community health worker program (N = 95)	Stress, educational attainment, isolation, depression screen, food and housing issues	Significant improvements were found in caregiver distress scores and children's understanding of their diagnosis.

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Table 1
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Author, year, country	Topics	Intervention/ target group	Data Sources, sample size	Outcomes	Findings
Ishiguro et al., 2016, Japan ^[29]	Support in nursery schools	Children with special needs	2476 NSTs working in 154 nurseries in Shimane and Kochi prefectures	Support realities and challenges	Future challenges to providing support to children are (1) raising awareness, (2) reducing regional disparities, (3) training NSTs to specialize in developmental disabilities, (4) training and retraining assistant NSTs, and (5) improving infant screening.
Lawson et al., 2011, USA ^[30]	Practice-based care coordination	Families of CSHCN	Family information 1 year after being introduced to the Massachusetts Department of Public Health Care Coordination Program; follow-up data for 130 (61 treatment, 69 comparison).	Access to support, satisfaction with services, parental mental and physical health	Families who received care coordination services believed that contact with their primary care providers and specialists was enhanced.
Lyles et al., 2017, USA ^[31]	Essential elements of care coordination	CSHCN	Summit attendees' responses about the system; 104 stakeholders (families, health care providers, community organizations)	Strengths and improvements that exist in the current system	Five key categories were identified as necessary for effective care coordination: communication, insurance, medical competence, provider knowledge, and family education.
Mann et al., 2021, USA ^[32]	Shared plans of care as a care coordination tool	CSHCN with behavioral and mental health conditions	Data were collected through a medical record review of CSHCN after shared plans of care provision (N = 15).	Number of hospitalizations, primary care visits, etc.	Implementation of the shared plans of care was associated with a significant decrease in primary care visits.
Matiz et al., 2021, USA ^[33]	Integrating nurse care managers in medical homes	CSHCN	Patients (n = 673) who received nurse-caregiver intervention at 4 medical facilities	Primary, subspecialty, emergency department, and inpatient health care utilization	Nurse care managers integrated into CSHCN medical homes have the potential to reduce emergency department visits, hospitalizations, and subspecialty visits.
McAllister et al., 2018, USA ^[34]	Care coordination using a shared plan of care approach	CYSHCN, (specifically neurodevelopmental disabilities)	Children with neurodevelopmental disabilities referred by subspecialists (N = 370)	Family empowerment, needs to be met, as the level of concern, and progress toward goals	Children/families gained skills in intervention, treatment, confidence, and navigation; the Riley Care Coordination Program achieved better care coordination with care neighborhood learning partnerships.
Ramirez et al., 2020, USA ^[35]	Care coordination and well-child care	CSHCN 15 months of age	Retrospective cohort analysis of 15-month-old patients (N = 1790) attending the clinic.	Well-childcare visit rate by 15 months of age	Pediatric care coordination was highly associated with well-child care schedule updates among CSHCN at 15 months of age and was more likely among children who received higher levels of care coordination.
Roman et al., 2020, USA ^[36]	Specific care coordination efforts	Families of CSHCN	Extracted and analyzed care coordination service data from 2682 CSHCN in the department's database.	Areas of care coordination (information services, education, etc.)	The most frequently needed areas across the study population, including informational services, were education, finances, medical/dental, social connections, and advocacy.
Taylor et al., 2013, USA ^[37]	A care coordination program	CSHCN referred to the care coordination counselor	91 patients and families served by care coordination counselors	Enjoyment of coordinated care, access to hospital resources and staff	Patients/families who received services from care coordination counselors benefited from receiving coordinated care, identifying key persons for coordination, and accessing coordination resources.
Ufer et al., 2018, USA ^[38]	Care coordination training program	Family of children with genetic conditions and other special health care needs	Eighty caregivers participated in the care coordination empowering families training.	Training satisfaction, training content, and training objectives	When families are educated about the systems they need to navigate and their role and power within them, they can make positive changes in how they interact with the systems that support their children.
Varda et al., 2018, USA ^[39]	Family social support networks	Families of children with special health care and developmental needs	Social network survey of 29 families who participated in the project	Role of personal social support network	Families identified a variety of formal and informal members, 61% of whom they rated as "very important." Informal network members (e.g., family, and friends) provided emotional support.
Cady et al., 2009, USA ^[40]	Focused care/support: Support using telehealth technology to enhance and facilitate care A telehealth nursing intervention	Children with complex health conditions	Children (n = 39) enrolled in the U Special Kids Program	Number of hospital admissions	The number of unplanned hospitalizations decreased from 74 in the first year of enrollment to 35 in the second year.

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Table 1
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Author, year, country	Topics	Intervention/ target group	Data Sources, sample size	Outcomes	Findings
Farmer et al., 2001, USA ^[41]	Interdisciplinary telehealth programs	CSHCN	A 1997–1998 survey of healthcare providers (N = 11) developing the program	Types of services, and health issues	The telemedicine service delivery system is versatile and has the potential to increase access to CSHCN and decrease fragmented care.
Hameed et al., 2021, India ^[42]	Telerehabilitation	Children with developmental disabilities.	Parents (N = 205) who participated in the study using a brief open-ended survey	Distance rehabilitation issues	Challenges included externalization issues and reduced effectiveness, while benefits included children's preference for equipment and increased time availability.
Hooshmand and Foronda, 2018, USA ^[43]	Integrating telemedicine visits	CSHCN	Traditional group (n = 110): families who received face-to-face pediatric specialty care; telemedicine group (n = 112): families who received telemedicine along with traditional face-to-face pediatric specialty care	Cost, compassionate, family-centered care	Significant differences were found in all variables, including distance traveled, travel costs, time missed, lost wages, childcare, lodging, other costs, and total family costs.
Marcin et al., 2004, USA ^[44]	Subspecialty care using telemedicine	CSHCN in rural areas	42 parents/guardians of CSHCN living in rural areas (55 CSHCN, 130 telemedicine consultations)	Satisfaction with care provided	All the parents/guardians rated satisfaction with telemedicine care as either “excellent” or “very good,” and most of the rural providers' surveys reported satisfaction with telemedicine as “excellent” or “very good.”
McConnochi et al., 2015, USA ^[45]	Acute care telemedicine	Children with regular and special health care needs	Telemedicine (483 and 10,008, respectively) consultations for CSHCN (n = 300) and children in regular childcare and schools (n = 1950)	Completion of telemedicine visits, duplication, adverse events	The observations supported the safety and effectiveness of Health-e-Access telemedicine for both CSHCN and children in regular childcare and schools.
Ming et al., 2023, USA ^[46]	Care coordination mobile app	Families of CSHCN	Parents/caregivers of CYSHCN targeted for enrollment (n = 40)	Parent-reported outcomes (e.g., care integration, health-related quality of life)	Digital health tools have the potential to improve care and outcomes for CYSHCN, but the evidence base is still being developed. The methodological rigor of early-stage digital health studies can be increased in the future.
Sezgin et al., 2022, USA ^[47]	A voice-enabled medical note-taking (diary) app (Speak Health)	Families of CSHCN	Parents (N = 41) who used the hospital network	Mobile app use, care coordination, and health care management, the app needs and expectations	More than half of caregivers reported that voice interaction with the app and the use of transcribed notes positively changed their preferences for the technology they use and how they track symptoms and health events at home.
Smith et al., 2023, USA ^[48]	Telehealth parent coaching	Families of CSHCN	11 families of CSHCN were recruited using convenience sampling, including 17 parents and 27 children	Family participation, cohesion, and adaptability	Within-group comparisons showed improvements in family participation, cohesion, adaptability, and communication. There was a positive relationship between family participation and cohesion, and between participation and adaptability.
Tennant et al., 2022, Canada ^[49]	Information management and communication in complex home care	Families of CSHCN aged under 18 years	A total of 7 families of CSHCN were recruited entirely through the web	Caregiver attributes and caregiver work domains	The design of digital health care systems and tools for complex home care has the potential to improve care coordination if they provide significant utility by adapting to the unique and dynamic home care environment.
Wong et al., 2023, USA ^[50]	Care coordination mobile app	Families of CYSHCN	Families (N = 38) of CYSHCN recruited by advocacy groups	Usability of the app using validated measures	The most highly rated functionality of the app was the ability to track progress toward short-term care goals defined by the patient and family; the app was highly rated in several areas of care coordination including the “home care” section.
Baron and Faubert, 2005, Canada ^[51]	Tai Chi Chuan reduces state anxiety and enhances mood	Children with special needs (upper elementary school children)	Three upper elementary school children (2 boys and 1 girl) attending a school for children with severe learning disabilities	Hyperactivity, anxiety, mood	Provided a useful framework for investigating the effectiveness of alternative mobility experiences for children with learning difficulties and, in some cases, increased anxiety and hyperactivity.
Dubois et al., 2023, Belgium ^[52]	Respite care services	Mothers of children with special health-care needs and disabilities	Interviews with 14 mothers who met the selection criteria	Family structure, mother's need for respite, barriers, and difficulties in accessing respite services	Respite services can be a way to meet the needs of parents of children and youth with special healthcare needs, but issues of availability and accessibility prevent equal access to services

(Continued)

Table 1
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Author, year, country	Topics	Intervention/ target group	Data Sources, sample size	Outcomes	Findings
McGrane et al., 2021, USA ^[53]	A group respite project	Families of children with special needs	CSHCN (n = 23) who participated in group respite care events	Parent and student reactions	Parents as well as nursing and physical therapy students mutually benefited from the ability to talk with other parents in similar situations, as it provided them relief from stress caused by caregiving.
Minor et al., 2006, Canada ^[54]	A mindfulness-based stress reduction program	Families of children with chronic conditions	Caregivers (n = 44) who were offered mindfulness-based stress reduction classes	Stress symptoms and mood disorders	A brief mindfulness-based stress reduction program for caregivers of chronically ill children was successful in significantly reducing substantial stress symptoms and mood disorders.
Nageswaran, 2009, USA ^[55]	Respite care services	Families of CSHCN	Respondent data (N = 38,831) from the 2001 National Survey of Children with Special Health Care Needs	Respite care needs and unmet care	A total of 3178 (8.8%) reported needing respite care in the past 12 months. Twenty-four percent of CSHCN who needed respite care did not receive services.
Whitmore and Snethen, 2018, USA ^[56]	Respite care services	Parents of CSHCN	Responses from 22 parents with children with special health care needs who participated in respite programs	Perceptions and experiences of respite care participation	Respite care can be beneficial to the marital relationship, as well as to children and their siblings with special care needs. It is also important to tailor respite care to the unique needs of the family.
Focused care/support: Peer and group support focusing on the power of the family or community					
Ainbinder et al., 1998, USA ^[57]	Parent-to-parent peer support	Parents of children with special needs	Parents with children with special needs (n = 24) from a subset of the larger quantitative study population	Impact and implications of matching trained and supportive parents	Parent-to-parent support creates a community of like-minded parents and provides an opportunity for parents to experience equal and reciprocal relationships with each other.
Ammari and Schoenebeck, 2015, USA ^[58]	Networked empowerment on Facebook	Parents of children with special needs	Interviews (N = 43) with 17 mothers and 28 fathers (two interviews were with married couple pairs, for a total of 45 participants)	Children's needs, impact on family life, use of social media sites	The intrapersonal component (how people think about themselves) includes reading about other parents' experiences and developing a belief that they can care for their own children.
Bjornstad et al., 2022, UK ^[59]	A peer-led group-based health promotion intervention	Parent carers of children with disabilities	Randomization of 92 participants who expressed interest in the program (47 intervention and 45 control)	Frequency of participation in activities for wellbeing, participants' own health care skills, health-related quality of life	It was possible to implement this program in the community. The number of parents who expressed interest indicates the need for such a program and the feasibility of recruiting them to a definitive clinical trial.
Dodds and Walch, 2022, USA ^[60]	Peer support for mothers	Mothers of young CSHCN	Participants (n = 5) who met the criteria out of 17 parents recruited via email	Experiences of connecting with supporters, communication with supporters, benefits of support	Participants in this study described improvements in their own emotional state and access to information, indicating increased competence, but they were hesitant to attribute improvements beyond themselves to parent-to-parent support.
Grandisson et al., 2023, Canada ^[61]	Online community forums with occupational therapists	Parents of a child considered to have special needs	Parents (n = 19) were invited to an online forum and an occupational therapist (n = 22)	Perceptions of how holding the forum affected the exchange of ideas	Strengthening the capacity of families with children considered to have special needs was a potential solution for providing occupational therapy services without placing undue burden on the family.
Pollock et al., 2022, USA ^[62]	Parent-to-parent peer support	Parents of CSHCN	Data from 203 interviews with 90 parents of CYSHCN with 3 family partners conducting interviews	Need for sustained care, coordination, stress management, and self-care	Family partners enhanced the health care team's ability to provide patient- and family-centered support to pediatric patients and their families through the provision of emotional and tangible support.
Roberts et al., 2015, Australia ^[63]	Support group program for siblings	Siblings of children with special needs	Participants (N = 42) in the SibworkS program	Sibling scores on the Strengths and Difficulties Questionnaire	Participants' decreased emotional and behavioral functioning and the severity of symptoms of children with special needs were associated with greater intervention effectiveness.
Roberts et al., 2016, Australia ^[64]	Intervention to promote the emotional and behavioral functioning of siblings	Siblings of children with disabilities and chronic health conditions	All program participants (N = 50) who returned at least one set of questionnaires	Emotional and behavioral functioning	Immediately after the program, parents of children who participated in SibworkS reported improved emotional and behavioral functioning, with medium to large effect sizes.
Santelli et al., 2000, USA ^[65]	Parent-to-parent programs	Parents of infants and young children with disabilities or special health care needs	Regional program (n = 29) in 18 states	Details and satisfaction regarding parent-child programs	Early intervention, providers' awareness of local and statewide parent-to-parent programs, and the coordination of early intervention efforts and parent-to-parent programs can improve the quality of support and services.

CSHCN = children with special healthcare needs, CYSHCN = children and youth with special healthcare needs, NST = nursery school teacher.

arranging and coordinating medical care and eliminate unmet service needs.^[20–22] Lin et al also confirmed that parents of CSHCN report better quality of healthcare.^[19] In addition, another study has highlighted the benefits to CSHCN, their families, and professionals who provide care by introducing concepts used in medical homes to hospitals and other institutions.^[23] Specifically, they reported shorter hospital stays, increased family satisfaction, and improved cost-effectiveness.^[23,24]

Meanwhile, challenges faced by agencies central to care coordination include difficulties in coordination between healthcare professionals and organizations as well as barriers related to the acquisition of knowledge (extensive knowledge of diseases, social resources, and coordination methods) by personnel providing care coordination.^[66] Care coordination involves linking CSHCN and their families to services and resources for optimal healthcare, including assessment, planning, implementation, monitoring, and support. The ultimate goal of care coordination is to facilitate timely service utilization, promote the continuity of care, and enhance the well-being of the child and family.^[67] In addition, a medical home serves as a specialized agency designed for CSHCN, aiming to provide comprehensive and continuous care.^[68]

3.4. Specialized personnel or programs for care coordination/integrated care

Fourteen studies were identified that primarily focused on personnel, programs, and care plans that integrated and coordinated care, rather than on the system of care provided by specialized agencies.^[26–39]

The professional personnel mentioned included nursing care managers, care coordinators, and community healthcare workers.^[28,33] These personnel were required to connect CSHCN and their families to various resources while practicing ongoing care coordination. A study conducted in Japan focused on child-care workers as occupations that support CSHCN, highlighting learning support methods and skills in communicating with the children's families as issues that need to be addressed.^[29] The possibility of achieving a high level of care coordination through sustained activities of personnel responsible for it was reported.^[33] In addition, close collaboration with other professions and care plan sharing with the child's family have been cited as important elements of this coordination.^[33]

Among the 14 studies, 6 provided insights into specific care programs or care plans.^[26,27,32,34,37,39] The shared plans of care aimed to facilitate family-centered care planning and care coordination using a mutually accessible platform for healthcare providers and families.^[32,34] The Care Coordination Program of Taylor et al tested the implementation of care coordination counselors and several support tools, including a community resource database.^[37] The tertiary care-community collaboration by Cohen et al evaluated enhanced collaboration between tertiary care institutions and community clinics to provide more cost-effective and higher-quality care.^[27] A review of comprehensive care plans by Adams et al emphasized the utility of care plans recommended in medical homes in centralizing the child's care, flattening the hierarchical relationship between care providers and families, and promoting information sharing and stronger relationships.^[26]

Two of the 6 cases focused on children with medical complexity, a subset of CSHCN with more complex needs.^[26,27] Adequate support for families and mental health support for professional personnel is crucial for enhancing the continuity of care models to provide quality care and support to children with distinctive needs, including children with medical complexity.^[26]

3.5. Support using telehealth technology to enhance and facilitate care

As described above, previous studies have examined specific programs and other aspects of care coordination

and comprehensive care delivery. Additionally, 11 studies investigated the use of tele-technology to enhance care delivery.^[40–50]

Many of these studies focused on telemedicine and information management technologies aimed at improving the quality of care and access to care.^[41,44,45,49] For instance, Marcin et al implemented telemedicine consultations using a video system in a rural community, which resulted in highly satisfactory family-centered care.^[44] Additionally, 2 studies examined nurse care coordination, case management via telephone, and telerehabilitation via online systems, highlighting certain benefits.^[40,42]

3.6. Care focused on reducing the psychological burden on the child and family

Six studies addressed care strategies aimed at alleviating the psychological burden on the child and family, such as respite care.^[51–56] Respite care ensures rest for the family and temporary relief from the care of the child and is essential for families of CSHCN.^[69] Dubois et al reported the effectiveness of respite care in such cases; however, they noted that the burden on families of CSHCN often exceeds their capacity, leading to physical and emotional exhaustion.^[51] Conversely, Nageswaran reported that approximately a quarter of families in need of respite care, especially families of CSHCN with unstable health statuses, do not receive it, emphasizing the need for strategies to enhance the provision of respite care.^[55] In addition to respite care, other types of care aimed at reducing the psychological burden on children and families have been identified, including mindfulness-based care.^[52,53]

3.7. Peer and group support focusing on the power of the family or community

Nonmedical support in the form of peer and group interactions also emerged as an important aspect of care and support, with 9 studies examining this type of support.^[57–65]

Research on community-based service systems and online community forums demonstrated their effectiveness in reducing family burden and enhancing access to healthcare services.^[58,59,61] Moreover, other studies have shown positive changes in emotional aspects owing to peer support among mothers and parents of CSHCN.^[57,60,62,65] Group programs targeting siblings of CSHCN were also noted for their potential to contribute to improvements in emotional and behavioral functioning among siblings.^[63,64]

4. Discussion

This review organized and integrated various broad categories of prior findings regarding the care and support for CSHCN and their families. Addressing the unmet needs of CSHCN requires a multifaceted care system that includes multidisciplinary medical care with coordination and integration of care and support for families.^[70–72]

Previous research has indicated that program models for the care coordination of CSHCN can be broadly classified into 2 categories: those where the primary focus of care coordination is within the community and those where the primary focus of care coordination is in a specialized institution (usually a hospital).^[13] While many studies in this review examined care systems centered on specialized agencies, one article focused on community-based programs rather than on specialized agencies. Furthermore, recently, research has been conducted on agencies and professionals specializing in care coordination and their collaboration with healthcare providers.^[28,33,37] Regardless of whether care coordination is managed by medical

institutions or other specialized institutions or professionals, dedicated personnel or institutions facilitating collaboration between CSHCN and their respective institutions throughout the lifespan of the CSHCN and their families would be useful. However, numerous studies have investigated the use of tele-technology and the strengthening of partnerships between core institutions and the community to enhance care programs and care coordination for CSHCN. Significant time burdens on caregivers and disparities in access to care have been identified as factors contributing to unmet care needs.^[5,7] Depending on the community and target cohort for which the care system is being expanded to CSHCN, the incorporation of tele-technology and stronger collaboration between core institutions and the community are critical elements to enhance the traditional care model.

Moreover, many recent studies have focused on respite care and group support, highlighting the importance of rest and recovery for families as part of the support system related to CSHCN. Furthermore, many studies that primarily focus on traditional care coordination have recognized the reduction of family burden as a coordination objective.^[22,27,36,73] Thus, incorporating family-focused respite care and group programs should be prioritized in the care of CSHCN. However, research into respite care and group programs is scattered and often limited to pilot studies and small sample sizes; therefore, there is a pressing need for ongoing practice-based and thorough evaluation studies.

To achieve a comprehensive care system that contributes to the welfare of the child-caring generation and their families and meets unmet needs, it is necessary to pursue care from multiple perspectives based on the characteristics of the specialized institutions and personnel providing the care and on the functions that provide continuous and smooth coordination tailored to the specific needs of the target cohort.

This study has some limitations. The care and support provided to CSHCN and their families are diverse, and outcomes vary. Therefore, this scoping review did not restrict the types of articles or research methodologies reviewed to organize the findings, and no critical appraisal or bias assessment was conducted. Future research should detail the specific care and support practices that are in place, accumulating evaluations and reviews of care programs or care coordination, because different cultures and social systems in different countries and regions have varying care and support systems.

In conclusion, this review organized and integrated prior research findings on the care and support for CSHCN and their families. In terms of care and support, in addition to programs focusing primarily on specialized agencies and professional personnel, other key areas included the use of tele-technology, family-focused respite care, and group programs. To enhance support systems for the well-being of CSHCN and their families, it is necessary to pursue a multi-faceted approach that facilitates continuous and smooth care coordination from various perspectives. For further research, reports on the profile of CSHCN in different countries and regions are required. Furthermore, studies should assess the specific and key elements of care programs and coordination efforts to provide evidence-based approaches to the strengthening of care systems. Specifically, detailed identification of the elements and characteristics of current systems of care and their contribution to reducing the burden and needs of CSHCN and their families and improving their quality of life will contribute to strengthening future systems of care.

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