

National Survey Data to Evaluate Case Management Services

A Systematic Review on Care Coordination Using the National Survey of Children With Special Health Care Needs

Hillary E. Swann-Thomsen, PhD, Ryan Lindsay, PhD, MPH, Seth Rourk, PharmD, Rylon Hofacer, PhD, and Elaine Nguyen, PharmD, MPH

ABSTRACT

Purpose of Study: The National Survey of Children with Special Health Care Needs (NS-CSHCN) is a publicly available resource that can be utilized to evaluate case management services such as care coordination. The authors sought to identify how researchers operationalize care coordination when utilizing this resource.

Primary Practice Setting: National outpatient survey.

Methodology and Sample: MEDLINE, PsycINFO, and CINAHL Complete were searched for studies that utilized the NS-CSHCN and report on outcomes of pediatric care coordination. Data from studies were extracted and results are descriptively reported.

Results: The authors screened 4,577 citations and included 19 studies reporting on the impact of pediatric care coordination. Care coordination was defined differently and was sometimes captured as part of the medical home definition, or assessed using study-specific questions on coordinated services and satisfaction with communication from the medical team.

Implications for Case Management Practice:

- National survey data such as the NS-CSHCN can be utilized to evaluate case management services such as pediatric care coordination.
- When utilizing national survey data, it is important to consider the operationalization and definition of services (e.g., care coordination) in the context of study intentions and the existing literature.
- Although care coordination has been operationalized differently, it is associated with favorable household and child-related outcomes.

Key words: *care coordination, child health services, health surveys, patient care management, pediatrics*

Children with special health care needs (CSHCN) are defined as children who have a chronic condition or are at an increased risk for a chronic condition, including physical, developmental, behavioral, or emotional conditions, and require health and health-related services of a type or amount beyond that which is required by children generally (McPherson et al., 1998). Children with special health care needs significantly utilize case management services and other health care resources. Families of CSHCN often report increased unmet needs and a lack of coordinated services and information (Hill et al., 2008; Miller et al., 2019). To understand services received or not received by CSHCN, the Maternal and Child Health Bureau of the U.S. Department of Health & Human Services developed the National Survey of Children with Special Health Care Needs

(NS-CSHCN; Centers for Disease Control and Prevention [CDC] National Center for Health Statistics, 2020).

The nationally distributed questionnaire includes core questions regarding access to medical homes, insurance status, and presence of adequate care coordination and sought to determine access to health care on a state level for CSHCN to inform programmatic funding and resource demand for both state and federal programs. At the time of its

Address correspondence to Elaine Nguyen, PharmD, MPH, 1311 East Central Dr, Meridian, ID 83642(nguyelai@isu.edu).

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Children with special health care needs (CSHCN) are defined as children who have a chronic condition or are at an increased risk for a chronic condition, including physical, developmental, behavioral, or emotional conditions, and require health and health-related services of a type or amount beyond that which is required by children generally.

development, the NS-CSHCN represented the largest study and the first national survey designed to allow for state level and federal estimates on the health of CSHCN (National Research Council and Institute of Medicine, 2004; van Dyck et al., 2002). A detailed explanation of the survey, including screening and questionnaire development, survey procedures, and distribution, can be found in the study by van Dyck et al. (2002). Since the implementation of the NS-CSHCN, the survey was distributed in 2001, 2005–2006, and 2009–2010, after which it was combined with the National Survey of Children's Health (NSCH) and has been distributed annually (CDC, 2015; Health Resources & Services Administration, 2019). Notably, the NS-CSHCN was updated as appropriate to capture changes in CSHCN approaches and expand household reach. For instance, the 2009–2010 survey, which was distributed until 2011, included questions regarding medication and treatment specifically for attention deficit disorder/attention deficit hyperactivity disorder but was also distributed to cell phone households rather than solely landline households as with previous versions (CDC, 2015).

Although the original intention of the survey was to provide information on the prevalence and impact of CSHCN, the survey has become a valuable tool beyond state and federal agencies and programs for CSHCN to highlight the role of care coordination within the medical home (e.g., McAllister et al., 2009; Turchi et al., 2009). The medical home model involves family-centered care, care coordination, accessible care, and a primary health care provider (McAllister et al., 2009). Care coordination is often the responsibility of case managers and an important facet of the medical home, associated with medical

complexity, need for multiple providers and services, and social determinants of health (Antonelli et al., 2008).

Research utilizing the NS-CSHCN has suggested that care coordination results in improved satisfaction with quality of care, reduced unmet needs, and improved communication with health care providers (Baruffi et al., 2005; Derigne & Porterfield, 2010; Hill et al., 2008; Wood et al., 2009). Care coordination is also associated with decreased financial burdens and loss of work, which are significant burdens faced by families of CSHCN (Turchi et al., 2009). Despite the evidence supporting the positive outcomes associated with care coordination, not all families of CSHCN receive adequate care coordination. For children with medical complexity, increased care coordination support could facilitate improved outcomes and decreased health care utilization, as well as reduce financial and nonfinancial burdens on families of CSHCN. To fully understand the need for care coordination, implementation of effective services, and outcomes in relation to CSHCN, more research is needed.

As a publicly available resource providing national-level data, the NS-CSHCN represents a valuable tool for improving the delivery of care coordination services. Given the benefits and frequent use of the NS-CSHCN, the authors sought to conduct a systematic review to examine the use of the NS-CSHCN in regard to pediatric care coordination. The objectives of the current review were to identify how care coordination was operationalized (defined) when utilizing the NS-CSHCN. To identify additional methodological considerations with use of this resource, outcomes, covariates, statistical methods, and relevant findings from included studies were also summarized.

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METHODS

This article is written with consideration for the PRISMA reporting guidelines (Moher et al., 2009). These guidelines provide a checklist and a flow diagram to assist in adequate reporting of systematic reviews and meta-analyses. The review protocol was not prospectively registered and no systematic review registration number is available.

Search Strategy

MEDLINE (via PubMed), PsycINFO (via Ebsco-Host), and CINAHL Complete (via EbscoHost) were searched from the start of each database (i.e., database inception) through November 13, 2017. These databases were selected on the basis of their relevancy to the topic and interdisciplinary citations. MEDLINE was selected because it represents the premier database from the National Library of Medicine and has a life science and biomedicine focus. The behavioral and social science aspect of PsycINFO, as well as CINAHL Complete's focus on nursing and allied health, was especially relevant to care coordination as this work is often led by nonphysician practitioners of the team (e.g., case managers). The search terms used captured the concepts of care coordination and pediatrics (see Appendix A). The authors conducted an updated search of databases from January 1, 2017, to August 29, 2019, using the previously described search terms with additional terms to capture use of the NS-CSHCN. No limits were applied to searches. Finally, the authors conducted a backward citation search of all included articles.

Study Selection

The subject of interest was studies utilizing the NS-CSHCN to evaluate pediatric care coordination. Study selection consisted of two parts: title/abstract screening of all identified citations and full-text review of citations that passed title/abstract screening. Both screening and review were completed independently by two investigators with discrepancies resolved through discussion and/or a third investigator. Articles were included if they were a study that utilized the NS-CSHCN, reported on the outcomes of care coordination, and published in the English language. As the current review was focused on the operationalization of care coordination, it had to be an independent variable in included studies. Studies focusing on transitions of care were excluded.

Data Collection

Two investigators worked independently to extract study data using a data collection worksheet and collected the following: title, last name of first author, survey year(s) used, inclusion criteria, definition of care coordination used, comparator to care coordination, outcomes, confounding/adjustment variables, and results. The data collection worksheet was developed through discussion by the authorship team of important items to extract. The worksheet was then piloted by four authors and applied to two studies. After piloting, the authors compared their extracted data and discussed discrepancies and interpretations of prompts. Questions were clarified and the worksheet then utilized to complete data collection for all studies. Investigators reviewed the data collected and resolved any discrepancies by discussion. Collected data were cleaned and organized in tables and descriptively reported in text. Outcomes of care coordination were organized by type: household/family, child (unmet needs, functional ability), and other.

Study Assessment

To develop an applicable study assessment tool for the included studies, the authors reviewed the Newcastle–Ottawa Quality Assessment Scale (NOS) for case control studies (Wells et al., 2021). By design of

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this review, all included studies utilized cross-sectional data from the NS-CSHCN. As such, some questions of the NOS would yield the same results. However, the authors noted differences in reported methodology across included studies and so compared studies based on whether care coordination was clearly defined, whether study design adequately controlled for covariates, and whether missing data were addressed (see Appendix B). These three areas cover selection, comparability, and exposure (as also done within the NOS). Two investigators independently applied study assessment questions for each included study, compared ratings, and resolved discrepancies through discussion. The authors considered the merits and limitations of the NS-CSHCN, and potential for risk of bias, when evaluating individual- and aggregate-level assessments of the overall work. Because no quantitative analysis (i.e., meta-analysis) was conducted, the authors did not exclude any studies in sensitivity/subgroup analyses in the reporting of results.

RESULTS

The authors identified 4,577 citations through MEDLINE, PsycINFO, and CINAHL and one additional citation through backward citation tracking (see Figure 1). Many citations were duplicates and 1,918 citations underwent title/abstract screening. After

title/abstract screening and full-text review, a total of 19 studies (see Table 1) were included.

The NS-CSHCN was used to examine the relationships between family and providers (Boudreau et al., 2014; Cordeiro et al., 2018; Ross et al., 2018; Turchi et al., 2009), financial or time burden to CSHCN families (Ghandour et al., 2011; Miller et al., 2015; Porterfield & DeRigne, 2011), impact on the family more broadly, including employment changes (Derigne & Porterfield, 2010; Katz et al., 2012; Ronis et al., 2015), and functional ability/status of the child (Miller et al., 2015; Ronis et al., 2015). In addition, the NS-CSHCN was used to examine particular subsets of the population surveyed, including regional populations (Baruffi et al., 2005; Hill et al., 2008), specific diagnoses (Cheak-Zamora & Farmer, 2015; Katz et al., 2012; Kenney & Kogan, 2011; Ronis et al., 2015), care provided by specialty health care professionals (Boudreau et al., 2014; Miller, 2014), and demographic characteristics (i.e., single mother families; Derigne & Porterfield, 2010), and by age and developmental delay/disability (Ross et al., 2018). The NS-CSHCN was also utilized to determine the need of additional services, including current report of unmet needs, or availability of care coordination (Aboneh & Chui, 2017; Baruffi et al., 2005; Cheak-Zamora & Farmer, 2015; Hill et al., 2008; Kenney & Kogan, 2011; Miller, 2014).

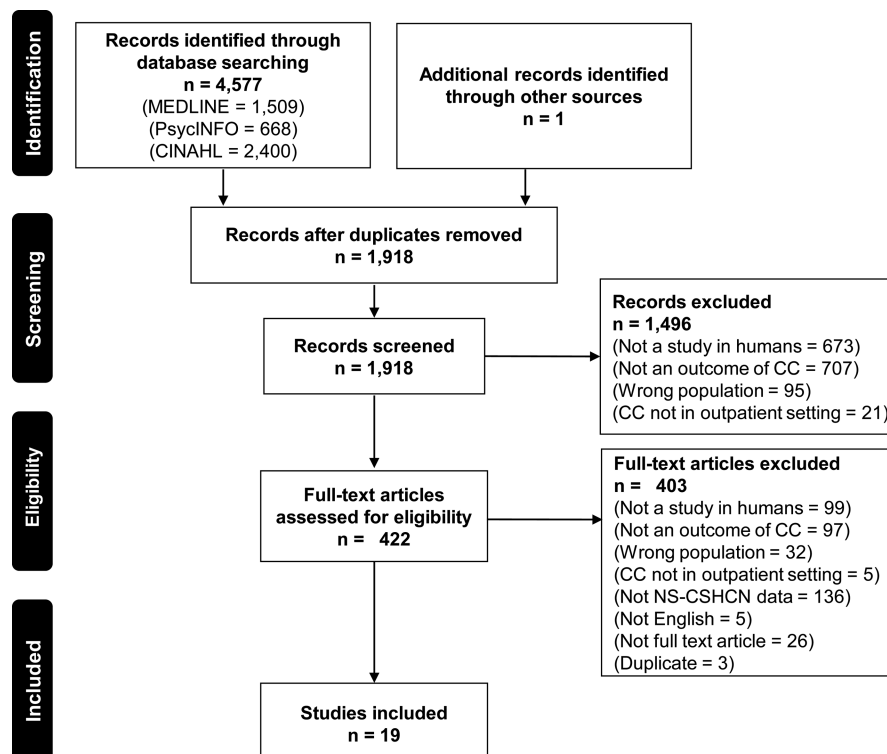


FIGURE 1
PRISMA flow diagram. CC = care coordination; CINAHL = Cumulative Index of Nursing and Allied Health Literature; NS-CSHCN = National Survey of Children with Special Health Care Needs.

TABLE 1
Characteristics of Included Studies

Study	Survey Cycle	Population	Care Coordination Definition	Comparator*	Outcomes Reported
Baruffi et al. (2005)	2001	Respondents within Hawaii	Coordinated, ongoing, comprehensive care within a medical home	No CC	Ease of using community-based services
Hill et al. (2008)	2001	Respondents within Massachusetts	Coordinated, ongoing, comprehensive care within a medical home	No CC	Perceived need for care from 14 health care and four family support services
Okumura et al. (2009)	2005–2006	Entire survey	Based on the patient-centered medical home	Ineffective CC	Work loss
Turchi et al. (2009)	2005–2006	Entire survey	Adequate CC, defined as parental report of (1) receiving assistance with coordinating child's care that was either needed or above needs and (2) being very satisfied with communication within the medical home	Inadequate CC	Family-provider relationships and outcomes
Derigne and Porterfield (2010)	2005–2006	Married couples and single mothers	CC assessed using questions (determined by study) on coordinated services and satisfaction with communication from medical team	No CC	Employment change
Chandour et al. (2011)	2005–2006	Entire survey	CC assessed using questions (determined by study) on coordinated services and satisfaction with communication from medical team	No CC	Parent-reported financial problems
Kenney and Kogan (2011)	2005–2006	Children with parent-reported speech and hearing difficulty	CC assessed using questions (determined by study) on coordinated services and satisfaction with communication from medical team	Ineffective CC	One or more unmet needs for therapy, hearing aids, or communication devices
Porterfield and DeRigne (2011)	2005–2006	Entire survey	Based on definition developed by the Child and Adolescent Health Measurement Initiative of receiving care coordination	No CC	Out-of-pocket medical costs
Katz et al. (2012)	2005–2006	Children with Type 1 diabetes	CC assessed using questions (determined by study) on coordinated services and satisfaction with communication from medical team	No CC	Impact of illness on family
Marti-Morales and Rohrer (2014)	2005–2006	Entire survey	CC assessed using questions (determined by study) on coordinated services and satisfaction with communication from medical team	No CC	Functional ability limitation
Boudreau et al. (2014)	2009–2010	Specialty and coordinated care recipients	Parental report of (1) receiving assistance with coordinating child's care that was either needed or above needs and (2) being very satisfied with communication within the medical home	No CC	Unmet need
Miller (2014)	2009–2010	Children enrolled in Medicaid or CHIP and mental health care or care from a specialty doctor	CC assistance from someone other than a family member or friend Satisfaction with communication from medical team	No CC Inadequate CC	Receipt of needed health care and timely access to mental and specialty health care services
Cheak-Zamora and Farmer (2015)	2009–2010	Children with autism spectrum disorder	Adequate CC, defined as adequate ratings from 10 composite survey items or a rating indicating that no CC was needed	No CC	Unmet need
Litt and McCormick (2015)	2009–2010	Entire survey	Effective CC, defined as parental report of sufficient coordination of care and communication between doctor and specialist, and satisfactory communication with medical team	No CC	Child functional status
Miller et al. (2015)	2009–2010	Entire survey	Based on the patient-centered medical home: accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care	No CC	Time burden
Ronis et al. (2015)	2009–2010	Children with ADHD	*Adequate care coordination if needed*	No CC	Family burden

(continues)

TABLE 1
Characteristics of Included Studies (Continued)

Study	Survey Cycle	Population	Care Coordination Definition	Comparator ^a	Outcomes Reported
Aboneh and Chui (2017)	2009–2010	Entire survey	Effective CC, defined as parental report of (1) receiving assistance with coordinating child's care that was either needed or above needs and (2) being very satisfied with communication within the medical home	All needs met CC	Unmet need for prescription medications
Cordeiro et al. (2018)	2009–2010	Entire survey	Adequate CC, defined as parental report of (1) receiving assistance with coordinating child's care that was either needed or above needs and (2) being very satisfied with communication within the medical home	Inadequate CC	Family–provider relationships and family/child outcomes ^b
Ross et al. (2018)	2009–2010	Children younger than 3 years, with a developmental disability or delay	CC assessed using questions (determined by study) on coordinated services and satisfaction with communication from medical team	Infants/toddlers who needed extra help coordinating care	Receipt of Part C services

Note. ADHD = attention deficit hyperactivity disorder; CC = care coordination; CHIP = Children's Health Insurance Program.

^aBased on the definition of care coordination used, the comparator may actually represent inadequate or ineffective care coordination but may not have been explicitly stated so in the study.

^bAdditional outcomes included receiving family-centered care, experiencing partnerships with professionals and satisfaction with services, problems getting referrals, missed school days, and emergency department visits.

Study Assessment

Seven included studies did not clearly define care coordination (see Appendix C). All included studies controlled to some extent for adjustment factors (medical complexity, demographics, and socioeconomic status) with 58% of included studies controlling for all three domains of adjustment factors (medical complexity, demographic, and socioeconomic status) to some extent. Studies were considered high risk of bias if missing data were not addressed and 47% of included studies did not address missing data.

Operationalization of Pediatric Care Coordination

Care coordination was defined differently by studies (see Table 1) and was sometimes captured as part of the medical home definition (Baruffi et al., 2005; CDC National Center for Health Statistics, 2020; Hill et al., 2008; Miller et al., 2015), or assessed using study-specific questions on coordinated services and satisfaction with communication from the medical team (Derigne & Porterfield, 2010; Ghandour et al., 2011; Katz et al., 2012; Kenney & Kogan, 2011; Marti-Morales & Rohrer, 2014; Ross et al., 2018). Some studies made the distinction of adequate or effective care coordination, often related to parental report of receiving assistance with coordinating child's care that was needed or above needs and satisfaction with communication with the medical home (Aboneh & Chui, 2017; Cheak-Zamora & Farmer, 2015; Cordeiro et al., 2018; Litt & McCormick, 2015; Turchi et al., 2009). The majority of included studies included no care coordination services received as the comparator group. However, based on the definition of care coordination used, the comparator may actually have represented inadequate or ineffective care coordination but may not have been explicitly stated so in the study.

Outcomes of Pediatric Care Coordination

The NS-CSHCN has been used to assess the impact of care coordination on a variety of outcomes affecting households ($n = 9$), as well as the child with special health care needs including unmet needs ($n = 6$), functional ability ($n = 2$), school absenteeism ($n = 3$), and emergency department visits ($n = 2$; see Table 2). Other outcomes assessed included ease of using community-based services ($n = 1$) and receipt of Part C services ($n = 1$). Covariates concurrently included in analyses were often presented using the framework of Andersen & Newman's (2005) health services theoretical model categories that include predisposing, enabling, and need factors. Nearly all studies controlled for at least one predisposing (e.g., child's sex,

TABLE 2
Outcomes, Covariates, Statistical Methods, and Relevant Findings With Care Coordination

Study	Covariates ^a					Findings
	Outcomes(s)	Predisposing	Enabling	Need	PCMH	
<i>Household outcomes</i>						
Okumura et al. (2009)	Work loss, a composite measure of cutting back or stopping work	Sex; age; race/ethnicity; family structure	Income; insurance; education;	Limitations; stability	Medical home	Effective CC was associated with lower odds of work loss (AOR = 0.6; 95% CI = 0.5–0.6 ^b)
Turchi et al. (2009) ^c	Receiving family-centered care; experiencing partnerships with professionals and satisfaction with services; problems getting referrals; OOP expenses; family financial burden; time coordinating care; impact on work/cut back on hours	Sex; age; race/ethnicity; family structure	Income; insurance; education	CSHCN criteria	Medical home	Those receiving adequate CC: More likely: • Receive family-centered care (AOR = 5.03; 95% CI = 4.55–5.55; $p < .001^b$) • Experience partnerships with professionals and satisfaction with services (AOR = 8.85; 95% CI = 7.97–9.81; $p < .001^b$) • Less likely: • Problems getting referrals (AOR = 0.19; 95% CI = 0.15–0.23; $p < .001^b$) • OOP expenses (>\$500 vs. ≤\$500; AOR = 0.57, 95% CI = 0.50–0.61; $p < .001^b$) • Family financial burden (AOR = 0.38; 95% CI = 0.34–0.43; $p < .001^b$) • Time coordinating care (>4 hr/week vs. ≤4 hr/week; AOR = 0.66, 95% CI = 0.59–0.74; $p < .001^b$) • Impact on work/cut back on hours (AOR = 0.47; 95% CI = 0.42–0.52; $p < .001^b$)
Derigne and Porterfield (2010) ^d	Change in parents' employment status (cut hours or stopped working)	Sex; age; race/ethnicity; Hispanic; immigrant family; only child; M-CSHCN; OFM	Income; insurance; SSI; gap—insurance; usual care; NP; geo location	Medical conditions; other conditions; severity; OOP costs; time; unmet respite; difficulty—services	Family-centered	There was a lower risk of cutting work hours and stopping work relative to no change in employment status in married couples (RRR = 0.57 and RRR = 0.69, respectively ^d) and single mothers (RRR = 0.61 and RRR = 0.57, respectively ^d) receiving CC
Ghandour et al. (2011)	Parent-reported financial problems experienced; reduction or cessation of employment	Sex; age; race/ethnicity	Income; insurance	Limitations		In CSHCN with emotional and behavioral needs, CC was associated with lower odds of financial problems (AOR = 1.15, 95% CI = 1.11–1.18, reduced from AOR = 1.22, 95% CI = 1.19–1.25; and AOR = 1.04, 95% CI = 1.02–1.07, reduced from AOR = 1.10, 95% CI = 1.07–1.13, respectively ^e) and employment changes (AOR = 1.13, 95% CI = 1.10–1.16, reduced from AOR = 1.20, 95% CI = 1.17–1.23; and AOR = 1.105, 95% CI = 1.03–1.108, reduced from AOR = 1.11, 95% CI = 1.08–1.13, respectively ^e)
Porterfield and DeRigne (2011)	Out-of-pocket medical costs incurred on behalf of CSHCN per \$1,000 of household income in the past year	Sex; age; OFM; only child; M-CSHCN	Income; insurance; education; delays—health care	Medical conditions; other conditions; severity; unmet needs		Parents of children who received CC services had lower odds of having any out-of-pocket costs; if costs were incurred, they were 32.55% lower (95% CI = 47.60–13.17%, $p < .01^f$) in those with private insurance and 15.18% lower (95% CI = 20.51–9.49%, $p < .01^f$) in those with public insurance than those incurred by children without care coordination services

(continues)

TABLE 2

Outcomes, Covariates, Statistical Methods, and Relevant Findings With Care Coordination (Continued)

Study	Covariates ^a				Findings
	Outcome(s)	Predisposing	Enabling	Need	
Katz et al. (2012) ^d	Family impact, measured overall and separately for: work restriction, financial impact, high medical expenses, time impact, and school absenteeism	Sex; age; race/ethnicity; language	Income; insurance; education		In children with Type 1 diabetes, CC was associated with less: <ul style="list-style-type: none"> Overall family impact (AOR = 0.36, 95% CI = 0.17–0.75, <i>p</i> = .007^b) Work restriction (AOR = 0.45, 95% CI = 0.25–0.80, <i>p</i> = .007^b) Financial impact (AOR = 0.34, 95% CI = 0.19–0.60, <i>p</i> = .0002^b) Impact on high medical expenses (AOR = 0.66, 95% CI = 0.36–1.18, <i>p</i> = .2 ^b), time (AOR = 0.83, 95% CI = 0.42–1.66, <i>p</i> = .6 ^b), and school absenteeism (AOR = 0.67, 95% CI = 0.33–1.34, <i>p</i> = .3 ^b) were nonsignificant
Miller et al. (2015)	Time burden, measured by time spent per week arranging/coordinating care, providing care, and both	Sex; age; race/ethnicity; language; family structure; M-CSHCN	Income; insurance; education; geo location	Limitations; stability; other dx	CC was associated with 32% lower odds (AOR = 0.68 ^b) of arranging/coordinating care, as well as lower odds of providing care, and both arranging/coordinating and providing care
Ronis et al. (2015) ^c	Family burden, defined as a positive response to family financial problems (yes/no) and/or family employment problems (yes/no)	Sex; age; race/ethnicity	Income; insurance; education	Severity; other dx	In children with ADHD, CC was associated with a 49% lower relative risk of financial problems (ARR = 0.51; 95% CI = 0.44–0.59; <i>p</i> < .001 ^b) and a 40% decreased relative risk of employment problems (ARR = 0.60; 95% CI = 0.54–0.67; <i>p</i> < .001 ^b)
Cordeiro et al. (2018) ^c	Receiving family-centered care; experiencing partnerships with professionals and satisfaction with services; problems getting referrals	Sex; age; race/ethnicity; family structure	Income; insurance; education	CSHCN criteria	Adequate CC was associated with increased odds of: <ul style="list-style-type: none"> Receiving family-centered care (AOR = 4.88; 95% CI = 4.39–5.42, <i>p</i> < .001^b) Experiencing partnerships with professionals and satisfaction with services (AOR = 8.32, 95% CI = 6.97–9.91, <i>p</i> < .001^b) Adequate CC was associated with reduced odds of problems getting referrals (AOR = 0.21, 95% CI = 0.17–0.26, <i>p</i> < .001 ^b)
<i>Child-related outcomes</i>					
Unmet needs					
Hill et al. (2008) ^d	Perceived need for care, including 14 health care and four family support services	Sex; Age; race/ethnicity; Hispanic	Income; insurance; education	Stability; severity; time	Receiving CC was associated with reduced unmet need for CSHCN in Massachusetts (AOR = 0.46, 95% CI = 0.23–0.90, <i>p</i> > .05 ^b) and the United States (AOR = 0.55, 95% CI = 0.49–0.62, <i>p</i> < .001 ^b); and for CSHCN with more severe conditions in the United States (AOR = 0.46, 95% CI = 0.36–0.58, <i>p</i> < .001 ^b)
Kenney and Kogan (2011) ^d	One or more unmet needs for therapy, hearing aids, or communication devices	Sex; age; race/ethnicity; Hispanic	Income; education		Not receiving effective CC was associated with one or more unmet needs for therapy, hearing aids, or communication devices (AOR = 3.98, 95% CI = 2.95–5.36 ^b)

(continues)

TABLE 2

Outcomes, Covariates, Statistical Methods, and Relevant Findings With Care Coordination (Continued)

Study	Covariates ^a					Findings
	Outcome(s)	Predisposing	Enabling	Need	PCMH	
Boudreau et al. (2014) ^d	Unmet specialty care (i.e., not having received all needed care from specialty doctors)	Sex; age; race/ethnicity; Hispanic	Insurance; education; medical expenses; preventive care			*Among children with special healthcare needs, care coordination is associated with lower odds of unmet specialty care needs regardless of whether care coordination was received within a medical home ^b (AOR = 0.22, 95% CI = 0.16–0.29) ^b ; without a medical home (AOR = 0.63, 95% CI = 0.47–0.86 ^b)
Miller (2014) ^d	Receipt of needed health care; timely access to needed mental and specialty health care services	Family structure	Geo location; usual care; NP	CSHCN criteria		Children (enrolled in Medicaid or CHIP) with a care coordinator receive mental health care and specialty care needs at a 4.3% ($p < .001^{\text{§}}$) and 10.2% ($p < .001^{\text{§}}$) higher rate, respectively, than those without a care coordinator. Timely services are obtained at a 2.0% ($p < .05^{\text{§}}$) and 4.2% ($p < .001^{\text{§}}$) higher rate for mental and specialty care, respectively Children (enrolled in Medicaid or CHIP) with adequate CC receive mental health care and specialty care needs at a 3.6% ($p < .001^{\text{§}}$) and 11.0% ($p < .001^{\text{§}}$) higher rate, respectively, than those without adequate CC. Timely services are obtained at a 3.6% ($p < .001^{\text{§}}$) and 7.7% ($p < .001^{\text{§}}$) higher rate for mental and specialty care, respectively
Cheak-Zamora and Farmer (2015) ^d	Unmet need, a composite measure of 12 variables representing an unmet need for one or more specialty services	Sex; age; race/ethnicity; OFM; family structure	Income; insurance; education; NP	Limitations; severity; other dx; unmet needs; genetic counseling; unmet respite	Family-centered; personal provider	In children with autism spectrum disorder, no CC increased the odds of unmet need (AOR = 2.64, 95% CI = 1.76–3.97, $p < .001^{\text{§}}$)
Aboneh and Chui (2017)	Unmet need for prescription medications	Sex; age; race/ethnicity; language	Income; insurance; education	Medical conditions		*Family report of unmet CC need was associated a statistically significant higher odds of unmet need for prescription medications (AOR = 3.81, 95% CI = 2.7–5.4) ^b
Functional ability						
Marti-Morales and Rohrer (2014)	Functional ability limitation, referring to capacity/ability to do activities that most children of same age can do	Sex; age; race/ethnicity	Income; insurance; education	Medical conditions		*CSHCN who did not receive CC had a 53% higher adjusted odds (AOR = 1.53, 95% CI = 1.21–1.94, $p < .001^{\text{§}}$) for a limitation in functional ability compared with CSHCN who received CC ^b
Litt and McCormick (2015)	Child functional status, measured by two composite variables (difficulty with activities or participation, and body functions)	Sex; age; race/ethnicity; language; family structure	Income; insurance; education; SSI	CSHCN criteria		Any CC (AOR = 0.82, 95% CI = 0.77–0.88 ^b) and that within a family-centered medical home (AOR = 0.71, 95% CI = 0.66–0.76 ^b) was associated with lower odds of functional disability (not within a medical home, AOR = 0.97, 95% CI = 0.87–1.07 ^b) The effect of CC on disability was reduced when unmet needs were added to the model (AOR = 0.97, 95% CI = 0.96–0.98 ^b)

(continues)

TABLE 2

Outcomes, Covariates, Statistical Methods, and Relevant Findings With Care Coordination (Continued)

Study	Outcome(s)	Covariates ^a				Findings
		Predisposing	Enabling	Need	PCMH	
<i>Other outcomes</i>						
Baruffi et al. (2005) ^d	Ease of using community-based services		Income; insurance	Limitations; severity; need	Family-centered	In Hawaii, not receiving CC was associated with increased odds of reporting difficulties in using community-based services (AOR = 2.95, 95% CI = 1.33–6.58) ^b
Turchi et al. (2009) ^e	Missed school days; ED visits	Sex; Age; Race/ethnicity	Income; Insurance; Education; Family structure	CSHCN criteria		Adequate CC was associated with fewer: <ul style="list-style-type: none"> Missed school days (>6 vs. ≤6 days; AOR = 0.77, 95% CI = 0.69–0.85, <i>p</i> < .001^b) ED visits (≥2 vs. <2 visits; AOR = 0.79, 95% CI = 0.70–0.88, <i>p</i> < .001^b)
Cordeiro et al. (2018) ^e	Missed school days; ED visits	Sex; age; race/ethnicity; family structure	Income; insurance; education	CSHCN criteria		Adequate CC was associated with fewer: <ul style="list-style-type: none"> Missed school days (>6 vs. ≤6 days; AOR = 0.68, 95% CI = 0.61–0.75, <i>p</i> < .001^b) ED visits (≥2 vs. <2 visits; AOR = 0.75, 95% CI = 0.67–0.84, <i>p</i> < .001^b)
Ross et al. (2018) ^d	Receipt of Part C services	Sex; age; race/ethnicity	Income; insurance; education	Limitations; severity; unmet needs	Family-centered	In CSHCN and development delays, effective CC was associated with reduced odds of Part C (AOR = 0.37, 95% CI = 0.17–0.77 ^b); this was not seen in CSHCN with developmental disability (AOR = 1.11, 95% CI = 0.51–2.38 ^b) and those with both developmental delays and disability (AOR = 0.80, 95% CI = 0.46–1.37 ^b)

Note: ADHD = attention deficit hyperactivity disorder; Age = age or age group; AOR = adjusted odds ratio; ARR = absolute risk reduction; CC = care coordination; CI = confidence interval; CSHCN criteria = number of children with special health care need criteria met; delays—health care = delays in getting health care; difficulty using services = difficulty using services; child needs; ED = emergency department; education = education or mother/caregiver's education or highest education in household; family-centered = care is family-centered; family structure = family structure or parent marital status or number of adults in household or number of nonchildren with special health care needs in household; gap—insurance = one or more months without insurance (past year); genetic counseling = genetic counseling needed; geo location = geographic location; Hispanic = child is Hispanic; income = household poverty or income; insurance = type of health insurance or child's health insurance status or health insurance gap; language = household language; limitations = activity limitations; medical conditions = child's medical conditions; medical expenses = medical expenses posing a financial burden to the family; medical home = having a medical home; M-CSHCN = multiple children with special health care needs; NP = no problem getting referrals; OFM = other family members with unmet health needs; only child = only child status; OOP costs = out-of-pocket costs; other conditions = child has both physical and emotional or developmental or behavioral conditions; other dx = other diagnoses or comorbidities; PCMH = patient-centered medical home; personal provider = personal doctor or nurse; preventative care = preventative care in the last 12 months; RRR = relative risk reduction; severity = severity of child's medical condition; sex = child's sex; SSI = family receives social security income; disability payments for child; stability = stability of child's health care needs; time = time spent providing/coordinating care or time affected by condition; unmet needs = child has unmet health need; unmet respite = family has unmet respite care needs; usual care = usual doctor and/or source of care.

^aCovariates were grouped using the Andersen and Newman's health services theoretical model categories.

^bLogistic regression.

^cOutcomes from this study are represented in multiple rows.

^dStudy population does not represent entire survey (see Table 1).

^eHeckman selection model.

^fPoisson regression.

^gPropensity score matching.

^hGeneralized estimating equations.

In terms of the impact of care coordination on household outcomes, it was associated with lower odds of parents or caregivers cutting back work hours, work loss, or employment changes. Care coordination was also associated with fewer financial problems overall, and specifically those receiving care coordination were less likely to have out-of-pocket expenses.

age, race/ethnicity), enabling (e.g., insurance, education-level of the parent), and need (e.g., severity of condition) factor. Approximately one-third of studies also included other aspects of the patient-centered medical home (e.g., receipt of family centered care) as a covariate when assessing the impact of care coordination on the outcome of interest.

In terms of the impact of care coordination on household outcomes, it was associated with lower odds of parents or caregivers cutting back work hours, work loss, or employment changes (Derigne & Porterfield, 2010; Ghandour et al., 2011; Katz et al., 2012; Okumura et al., 2009; Ronis et al., 2015). Care coordination was also associated with fewer financial problems overall (Ghandour et al., 2011; Katz et al., 2012; Ronis et al., 2015; Turchi et al., 2009), and specifically those receiving care coordination were less likely to have out-of-pocket expenses (Porterfield & DeRigne, 2011; Turchi et al., 2009) and had lower out-of-pocket costs if costs were incurred (Porterfield & DeRigne, 2011). Care coordination was not associated with experiencing high medical costs, defined in the study by Katz et al. (2012), as the family paying more than \$1,000 for their child's medical care. Turchi et al. (2009) and Cordeiro et al. (2018) utilized different cycles of the NS-CSHCN (2005–2006 and 2009–2010, respectively) to report that those receiving care coordination were more likely to receive family-centered care and to experience partnerships with professionals and satisfaction with services and less likely to report problems getting referrals for services. Receiving care coordination was associated with families spending less time coordinating care by Turchi et al. (2009) and Miller et al. (2015) but not by Katz et al. (2012).

Care coordination was associated with various health outcomes for the CSHCN. Overall, those

Care coordination was associated with various health outcomes for the CSHCN. Overall, those receiving care coordination appeared to have reduced unmet needs.

receiving care coordination appeared to have reduced unmet needs; this was true in the different populations of children: those with more severe conditions (Hill et al., 2008), parent-reported speech and hearing difficulty (Kenney & Kogan, 2011), receiving specialty care (Boudrea et al., 2014), with Medicaid or the Children's Health Insurance Program (CHIP) and mental or specialty care (Miller, 2014), and autism spectrum disorder (Cheak-Zamora & Farmer, 2015). Unmet care coordination was associated with higher odds of unmet need for prescription medications (Miller et al., 2015). Two studies also found favorable outcomes with the impact of care coordination on functional ability (Litt & McCormick, 2015; Marti-Morales & Rohrer, 2014).

In both the 2005–2006 and 2009–2010 cycles of the survey, adequate care coordination was associated with fewer emergency department visits and missed school days (Cordeiro et al., 2018; Turchi et al., 2009). However, in children with Type 1 diabetes, it was not associated with a significant impact on school absenteeism (Marti-Morales & Rohrer, 2014). Finally, in specific populations, care coordination was also favorably associated with ease of using community-based services and reduced odds of Part C services (Baruffi et al., 2005; Ross et al., 2018).

DISCUSSION

The NS-CSHCN can be utilized to evaluate care coordination services, although operationalization of care coordination is often defined differently. Despite this, in the studies included in the current work, the authors found that care coordination was still associated with favorable household and child-related outcomes.

The NS-CSHCN utilized the patient-centered medical home operationalization of care coordination developed by the American Academy of Pediatrics to determine the level of care coordination received by families of CSHCN (Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2002). These questions centered around whether CSHCN families received some form of assistance with coordinating their child's care, the level of satisfaction of the family with services and communication from the child's medical

team, including primary providers and specialists, and satisfaction with communication from the medical team to educational program or similar programs. Although care coordination-related questions are defined within the NS-CSHCN, the included studies still defined and classified care coordination differently. Provided definitions varied from a broad overview of what was considered care coordination to a clear outline of the specific question and criteria used to determine whether care coordination was received by the families. In addition, some studies also looked at more specific questions rather than the composite score of care coordination presence, further breaking down what they considered to be care coordination for their specific analyses and research question.

Given the varying ways that the definition of care coordination may be operationalized, thoughtful consideration to study objectives and outcomes is required when evaluating services. It is also important to explicitly define care coordination, including the questions and how they were used in operationalizing the definition. Although the delivery of care coordination (or its adequacy or effectiveness) may be measured as nominal data, it may also be ordinal or even continuous in some situations. The 2018 NSCH Guide to Topics and Questions Asked groups six questions under the topic of care coordination (survey questions D7–D12; Data Resource Center for Child and Adolescent Health, 2019a). Some of these questions are nominal (e.g., during the past 12 months, did anyone help you arrange or coordinate this child’s care among the different doctors or services that this child uses?), whereas others are ordinal (e.g., during the past 12 months, how satisfied were you with the communication between this child’s doctors and other health care providers?). Survey question F6 (categorized in the “providing for this child’s health” topic) also asks survey respondents to estimate “in an average week, how many hours do you or other family members spend arranging or coordinating health or medical care for this child ...?” The answer options for this question are ordinal. A consistent definition that can be applied across future studies evaluating this topic utilizing the NS-CSHCN or the NSCH is needed. Consistency among studies may allow for better comparison of data as well as greater generalizability of results.

Care coordination models may be delivered along the continuum of care settings (e.g., primary or acute care) and by different personnel (e.g., case managers or nurses; Guided Care, 2020; Hajewski & Shirey 2014; Rush University Medical Center, 2020). Unfortunately, care coordination–related questions in the NSCH no longer inquire about who (e.g., friend, case manager, etc.) is helping to coordinate care, as

done in the NS-CSHCN (CDC, 2011; Data Resource Center for Child and Adolescent Health, 2019b). Such information may be useful to determine whether care coordination delivery and/or outcomes differ by the provider of services. The questions and language of the NSCH could evolve to further elucidate the model of care coordination received by the families of CSHCN to further understanding of how these models may impact outcomes of care coordination.

Those providing care coordination services may have different educational backgrounds, work experience, and training. The New York Academy of Medicine has recommendations for a *qualified* care coordinator, which include standards for education, experience, training, essential functions, skills, knowledge, attitudes, and values (Rush University Medical Center, 2020). The ability to determine such specifics of care coordinators is currently outside the scope of national survey data sets, such as the NS-CSHCN or the NSCH, but presents opportunities for further research.

As a multicomponent concept, care coordination can be difficult to measure in survey research and in practical application. The Agency for Healthcare Research and Quality (AHRQ) has developed a survey to collect and understand adult experiences with care coordination, the Care Coordination Quality Measure for Primary Care (Agency for Healthcare Research and Quality, 2016). However, this is a 43-item survey, which may limit its use. The AHRQ Care Coordination Measure Atlas also provides measures of care coordination for those who work in this field (McDonald et al., 2014). These tools provide additional resources for those studying care coordination.

Limitations

This work is not without limitations. As with any systematic review, the quality of the work is dependent on the quality of included studies. All of the included studies represent cross-sectional data, given the nature of the NS-CSHCN. Given that most of the results found care coordination to be associated with positive outcomes, publication bias may exist. There is also a delay in availability of national survey data as well as research conducted and published using these data. As a result, several included studies were published more than 5 years ago. This work included studies only with care coordination as the independent variable as were interested in the operationalization and outcomes of care coordination. Some of the included studies independently evaluated care coordination but as a single component of the larger medical home model. In some studies, the impact of care coordination may not have been the primary study objective,

so key details related to analysis of care coordination may not have been reported. In addition, it may be of interest to others to also evaluate care coordination as a dependent variable. Lastly, as previously noted, the NS-CSHCN is now combined with the NSCH. This work evaluates only the NS-CSHCN, which was last conducted in 2009–2010. Despite this time delay, research using the NS-CSHCN continues to be published and the data presented here are still applicable to the currently administered NSCH.

Implications for Case Management Practice

Utilizing national survey data, such as the NS-CSHCN, allows for researchers and health care professionals to evaluate case management services, such as pediatric care coordination. Better understanding the need and availability of said services allows for health systems, including outpatient clinics and independent contractors, to efficiently allocate services based on the needs of community populations. Importantly, when utilizing national survey data, it is important to consider the operationalization and definition of services, such as care coordination, in the context of study intentions and the existing literature. Despite differences in operationalization of care coordination, studies have consistently demonstrated favorable associations with both household and child-related outcomes.

CONCLUSION

Despite the existing research emphasizing the importance of care coordination services for CSHCN, these families continue to report unmet needs, often despite family structure, socioeconomic status, or insurance status, particularly in children who have mental health diagnoses (Miller et al., 2019). As care coordination services continue to expand to inpatient and outpatient clinics and incorporate various health care professionals, such as social workers and nurse practitioners (Ross et al., 2019; Ruggiero et al., 2019), national survey data, such as the NS-CSHCN (now the NSCH), serve as a resource for better understanding care coordination and its impact on household and child outcomes, and continue to inform stakeholders of whether the needs of families of CSHCN are receiving adequate services. It is important for data users to consider the operationalization of care coordination in the context of their study intentions and the existing literature.

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Hillary E. Swann-Thomsen, PhD, was a postdoctoral fellow in the Idaho Center for Health Research at Idaho State University during the time of this work. She is currently an applied research scientist at St. Luke's Health System. Her research focuses on improving quality of care in vulnerable patient populations.

Ryan Lindsay, PhD, MPH, is an associate professor in the Department of Community and Public Health at Idaho State University with interests in the household production of health, healthcare access, and the interaction between substance use and infectious diseases. His research highlights the health of addicted, deaf, homeless, immigrant, and sex worker populations.

Seth Rourk, PharmD, was a student pharmacist at Idaho State University College of Pharmacy during the time of this work. He is currently an instructor and affiliate faculty in the Department of Pharmacy Practice at Idaho State University.

Rylon Hofacer, PhD, was a postdoctoral fellow in the Idaho Center for Health Research at Idaho State University during the time of this work. He is currently a healthcare economics analyst at Blue Cross of Idaho.

Elaine Nguyen, PharmD, MPH, is an assistant professor in the Department of Pharmacy Practice at Idaho State University. She is interested in chronic disease management, health services–related research, and the use of technology in patient care.

Appendix A Search Terms

Search	Terms
First search from the start of each database through November 13, 2017	("coordinated care" OR "care coordination" OR "collaborative care" OR "interdisciplinary care") AND (pediatric OR youth OR child OR children OR infan* OR adolescen* OR teen* OR "young adult")
Updated search from January 1, 2017, to August 29, 2019	("coordinated care" OR "care coordination" OR "collaborative care" OR "interdisciplinary care") AND (pediatric OR youth OR child OR children OR infan* OR adolescen* OR teen* OR "young adult") AND ("NS-CSHCN" OR "NSCSHCN" OR "NS CSHCN" OR "national survey" OR "NSCH")

Appendix B Assessment Questions^a

1. Was care coordination clearly defined?
 - a. Yes, corresponds to NS-CSHCN questions related to care coordination and/or provides details related to definition*
 - b. No description
2. Did the study design adequately control for covariates?
 - a. Study controlled for all three of the following variables: medical complexity, demographic (e.g., age, gender, race/ethnicity), and socioeconomic status (e.g., household income, insurance)**
 - b. Study controlled for one or two of the following variables: medical complexity, demographic, or socioeconomic status*
 - c. Study did not control for any of the following variables: medical complexity, demographic, or socioeconomic status
3. Was missing data addressed?
 - a. Yes*
 - b. No

^aAsterisks correspond to those assigned to each article (see Appendix C for results).

Appendix C Results of Assessment Questions^a

Study	Definition of Care Coordination	Control for Covariates	Missing Data
Baruffi et al. (2005)	*	*	
Hill et al. (2008)		**	*
Okumura et al. (2009)		**	
Turchi et al. (2009)	*	**	*
Derigne and Porterfield (2010)		**	*
Ghandour et al. (2011)	*	*	
Kenney and Kogan (2011)	*	*	
Porterfield and DeRigne (2011)		**	*
Katz et al. (2012)	*	*	
Marti-Morales and Rohrer (2014)	*	**	
Boudreau et al. (2014)	*	*	*
Miller (2014)	*	*	*
Cheak-Zamora and Farmer (2015)		**	
Litt and McCormick (2015)	*	**	*
Miller et al. (2015)		**	*
Ronis et al. (2015)		**	*
Aboneh and Chui (2017)	*	*	
Cordeiro et al. (2018)	*	*	
Ross et al. (2018)	*	**	*

^aSee Appendix B for assessment questions and results that correspond with assigned asterisks.

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INSTRUCTIONS

National Survey Data to Evaluate Case Management Services: A Systematic Review on Care Coordination Using the National Survey of Children With Special Health Care Needs

Instructions:

- Read the article. The test for this CE activity can only be taken online at www.nursingcenter.com/ce/PCM.
- You will need to create (its free!) and login to your personal CE Planner account before taking online tests. Your planner will keep track of all your Lippincott Professional Development online CE activities for you.
- There is only one correct answer for each question. A passing score for this test is 7 correct answers. If you pass, you can print your certificate of earned contact hours and access the answer key. If you fail, you have the option of taking the test again at no additional cost.
- For questions, contact Lippincott Professional Development: 1-800-787-8985.

Continuing Education Information for Certified Case Managers:

This Continuing Education (CE) program is provided by Lippincott Professional Development and has been preapproved by the Commission for Case Manager Certification (CCMC) to provide CE credit to Certified Case Managers (CCMs) for 1.0 contact hours. This CE program is approved for meeting the requirements for certification renewal.

Registration Deadline: May 1, 2023

Continuing Education Information for Certified Professionals in Healthcare Quality (CPHQ):

This continuing education (CE) activity is provided by Lippincott Professional Development and has been approved by the National

Association for Healthcare Quality (NAHQ) for 2.0 CE Hours. CPHQ CE Hours are based on a 60-minute hour. This CE is approved for meeting requirements for certification renewal.

This CPHQ CE activity expires on May 1, 2023.

Continuing Education Information for Nurses:

Lippincott Professional Development will award 2.0 contact hours for this continuing nursing education activity.

LPD is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

This activity is also provider approved by the California Board of Registered Nursing, Provider Number CEP 11749. LPD is also an approved provider by the District of Columbia, Georgia, and Florida CE Broker #50-1223.

Registration Deadline for Nurses: May 1, 2023

Disclosure Statement:

The author and planners have disclosed no potential relevant financial relationships or otherwise.

Payment and Discounts:

- The registration fee for this test is \$21.95
- CMSA members can save 25% on all CE activities from *Professional Case Management* ! Contact your CMSA representative to obtain the discount code to use when payment for the CE is requested.

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