

Need and Unmet Need for Care Coordination Among Children With Mental Health Conditions



WHAT'S KNOWN ON THIS SUBJECT: Although care coordination has been associated with lower health care costs and improved outcomes for vulnerable children, little is known about the extent of need and factors associated with unmet need for care coordination among children with mental health conditions.



WHAT THIS STUDY ADDS: Children with mental health conditions have substantial need and unmet need for care coordination. Unmet need is more likely for families with children with anxiety disorder and less likely for those who report social support and family-centered care.

abstract

FREE

OBJECTIVE: To determine prevalence and correlates of need and unmet need for care coordination in a national sample of children with mental health conditions.

METHODS: Using data from the 2007 National Survey of Children's Health, we identified children aged 2 to 17 years with ≥ 1 mental health condition (attention-deficit/hyperactivity disorder, anxiety disorder, conduct disorder, or depression) who had received ≥ 2 types of preventive or subspecialty health services in the past year. We defined 2 outcome measures of interest: (1) prevalence of need for care coordination; and (2) prevalence of unmet need for care coordination in those with a need. Logistic regression models were used to estimate associations of clinical, sociodemographic, parent psychosocial, and health care characteristics with the outcome measures.

RESULTS: In our sample ($N = 7501$, representing an estimated 5 750 000 children), the prevalence of having any need for care coordination was 43.2%. Among parents reporting a need for care coordination, the prevalence of unmet need was 41.2%. Higher risk of unmet need for care coordination was associated with child anxiety disorder, parenting stress, lower income, and public or no insurance. Parents reporting social support and receipt of family-centered care had a lower risk of unmet need for care coordination.

CONCLUSIONS: Approximately 40% of parents of children with mental health conditions who reported a need for care coordination also reported that their need was unmet. Delivery of family-centered care and enhancing family supports may help to reduce unmet need for care coordination in this vulnerable population. *Pediatrics* 2014;133:e530–e537

AUTHORS: Nicole M. Brown, MD, MPH, MHS,^a Jeremy C. Green, PhD, MPhil,^b Mayur M. Desai, PhD, MPH,^{a,c} Carol C. Weitzman, MD,^d and Marjorie S. Rosenthal, MD, MPH^{a,c,d}

^aRobert Wood Johnson Foundation Clinical Scholars Program and ^dDepartment of Pediatrics, Yale School of Medicine, New Haven, Connecticut; ^bDepartment of Health Management and Policy, Saint Louis University, St Louis, Missouri; and ^cDepartment of Chronic Disease Epidemiology, Yale School of Public Health, New Haven, Connecticut

KEY WORDS

care coordination, family-centered care, health care delivery, medical home, mental health

ABBREVIATIONS

ADHD—attention-deficit/hyperactivity disorder
CI—confidence interval
RR—relative risk

Dr Brown conceptualized and designed the study, acquired the data, analyzed and interpreted the data, and drafted the initial manuscript; Dr Green contributed to the design of the study, analyzed and interpreted the data, and revised the manuscript for important intellectual content; and Drs Desai, Weitzman, and Rosenthal contributed to the design of the study, interpreted the analysis, and revised the manuscript for important intellectual content. All authors approved the final manuscript as submitted.

www.pediatrics.org/cgi/doi/10.1542/peds.2013-2590

doi:10.1542/peds.2013-2590

Accepted for publication Dec 18, 2013

Address correspondence to Nicole M. Brown, MD, MPH, MHS, The Children's Hospital at Montefiore, Family Care Center, 3444 Kossuth Ave, Bronx, NY 10467. E-mail: nicolebr@montefiore.org

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2014 by the American Academy of Pediatrics

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Dr Brown was supported by the Robert Wood Johnson Foundation Clinical Scholars Program, and Dr Green was supported by an Agency for Healthcare Research and Quality T32 training grant.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

Although one-quarter of patients seen in pediatric primary care settings have a chronic mental health condition,¹ only 1 in 5 receive mental health treatment.² These children and their families are more likely to have trouble accessing specialty care for comorbid medical conditions, and they often experience social complexities that demand coordination across multiple systems of care.³ Without access to processes and services that effectively bridge their mental health, medical, and social needs, children with mental health conditions are at high risk for unnecessary hospitalizations and emergency department use,⁴ suboptimal academic outcomes,⁵ involvement with the child welfare and criminal justice systems,³ and death from suicide.^{3,5}

Through authority granted by the Patient Protection and Affordable Care Act, state Medicaid programs and providers may establish “health homes” for individuals with chronic conditions.⁶ Health homes are expected to provide a cost-effective model of interprofessional collaboration for individuals with chronic physical and mental health conditions.⁷ Care coordination, “a process that links children and youth with special health care needs and their families with appropriate services and resources in a coordinated effort to achieve good health,”⁸ has been described as an essential element of the health home. Care coordination has been shown to be cost-effective,⁹ reduce emergency department use and hospitalizations,¹⁰ improve health outcomes,¹¹ enhance efficiency of systems,¹² help patients and families more effectively use the health care system,^{12,13} and improve satisfaction with the care experience.¹⁴ Although there will be increased national investments in care coordination targeting children with mental health conditions,¹⁵ little is known about perceived need and unmet need for care coordination in this

population.¹⁶ An enhanced understanding of which patients are most likely to have suboptimal care coordination experiences is critical to help target limited resources and design coordination strategies within health homes and other service delivery settings. Accordingly, we sought to determine the prevalence and correlates of unmet need for care coordination in a national sample of children with mental health conditions.

METHODS

Data Source and Study Sample

Data were obtained from the 2007 National Survey of Children’s Health,¹⁸ a population-based, cross-sectional telephone survey that queries parents or other primary caregivers about a selected child’s health, family characteristics, and about their need for, and use of, health services. The study sample for this analysis of need and unmet need for care coordination included children aged 2 to 17 years who: (1) had at least 1 of 4 chronic mental health conditions (attention-deficit/hyperactivity disorder [ADHD], anxiety disorder, conduct disorder, or depression) that had lasted or was expected to last ≥ 12 months; and (2) used ≥ 2 health care services (preventive medical care, preventive dental care, mental health care, and subspecialty care) in the past 12 months.

The Yale School of Medicine Institutional Review Board found the study exempt from human subject review.

Measures

Need and Unmet Need for Care Coordination

The outcomes of interest were as follows: (1) prevalence of need for care coordination; and (2) prevalence of unmet need for care coordination. Parents of children who used ≥ 2 of the aforementioned services were asked

a sequence of 3 questions about provision of care coordination: “Does anyone help you arrange or coordinate care among the different doctors that the child uses?”; “During the past 12 months, have you felt you could have used extra help arranging or coordinating the child’s care among the different health care providers or services?”; and “During the past 12 months, how often did you get as much help as you wanted with arranging or coordinating care? Would you say never, sometimes, or usually?”

We created 3 mutually exclusive categories of need based on parents’ responses: no need, met need, and unmet need (Fig 1). Those who reported that no one helped them coordinate their child’s care and that they did not need extra help were categorized as having no need for care coordination. Met need was defined as either: (1) having someone who helped with coordinating care and not needing extra help; or (2) needing extra help and usually receiving as much help as wanted. Lastly, unmet need was defined as only sometimes or never receiving as much help as wanted with coordinating their child’s care.

Sociodemographic, Clinical, and Parent Psychosocial Characteristics

We examined sociodemographic, clinical, and parent psychosocial characteristics that may influence need for care coordination services.^{10,11,20} Our selection of variables was guided by the Behavioral Model for Vulnerable Populations.²¹ Sociodemographic characteristics included child’s age, gender, race/ethnicity, and insurance status (private, public, or uninsured); household income (based on percentage of the federal poverty level); primary language spoken in the home (English or non-English); and family structure (2-parent [biological or adopted], 2-parent stepfamily, single mother, or other).

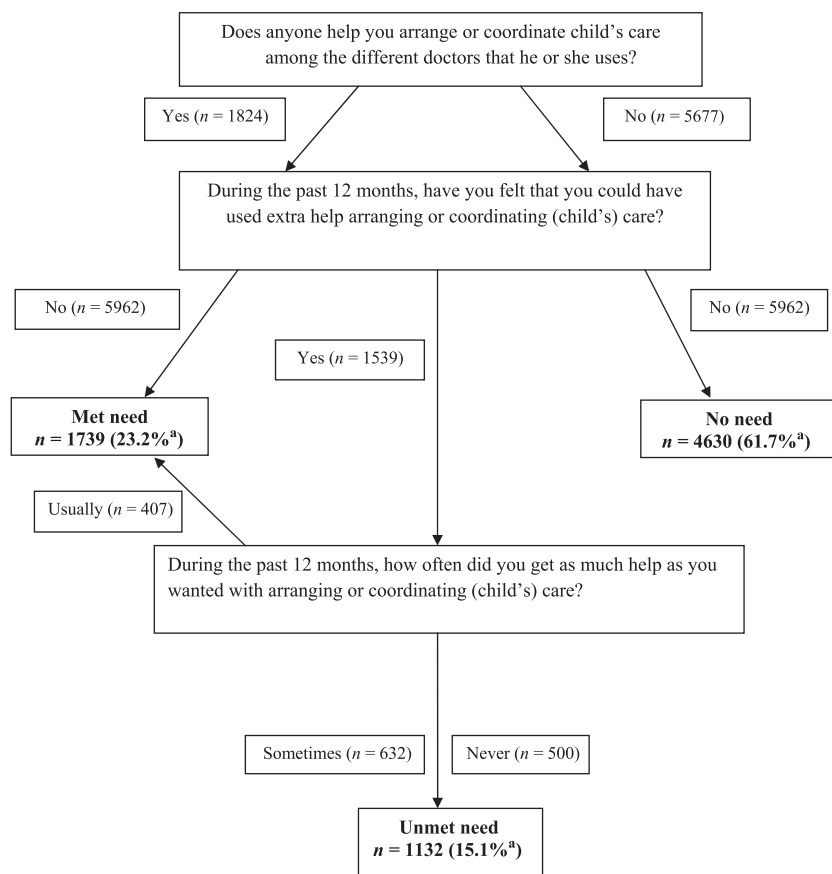


FIGURE 1 Determining the prevalence of care coordination need among children with a mental health condition ($N = 7501$). ^a Unweighted percentages are shown in parentheses.

Clinical characteristics included the 4 chronic mental health conditions (ADHD, anxiety disorder, conduct disorder, and depression), presence of ≥ 1 physical health condition (asthma, diabetes, seizure disorder, brain injury or concussion, speech problem, vision problem not corrected with glasses, and hearing problem), and presence of autism or autism spectrum disorder.

We examined parental characteristics that have been shown to be associated with a need for care coordination among children and youth.^{10,22} Parental psychosocial characteristics included ratings of maternal and paternal mental health, parenting stress, presence of social support, and maternal and paternal level of education. To determine presence of parenting stress,

parents were asked: “During the past month, how often have you felt [child] is much harder to care for than most children his/her age?” “During the past month, how often have you felt (he/she) does things that really bother you a lot?” and “During the past month, how often have you felt angry with (him/her)?” If parents answered “usually” or “always” to ≥ 1 of these questions, they qualified as having parenting stress. We measured parent social support by examining responses (“yes” versus “no”) to the question, “Is there someone you can turn to for day-to-day emotional help with parenthood/raising children?”

Health Care Characteristic

The health care characteristic that we examined was receipt of family-centered

care. The family-centered care composite indicator measures parent responses (never, rarely, sometimes, usually, or always) to 6 experience-of-care items.²³ These items include a physician or health care professional who: (1) spends enough time with child; (2) listens carefully to parents; (3) is sensitive to family values/customs; (4) provides needed information; (5) treats parents as partners in child’s health care; and (6) if needed, provides an interpreter. If parents answered “usually” or “always” to all of these questions, they qualified as having family-centered care.

Analysis

The analysis for this study proceeded in 3 steps. First, descriptive statistics were used to summarize the characteristics of the sample. Second, parents’ survey responses were analyzed to determine the prevalence of need and the proportion of unmet need for care coordination. Third, the associations between the independent variables of interest and each of the 2 outcome measures were assessed. We used binomial logistic regression and multinomial logistic regression to model, respectively, the prevalence of need and the proportion of unmet need.^{24,25} We additionally adjusted for state of residence and missing data.^{24,25} Results were interpreted as risk ratios using the method of Kleinman and Norton.²⁶ All analyses were conducted by using Stata version 12 (Stata Corp, College Station, TX) to account for the weighting and complex survey design.²⁶

RESULTS

Description of the Sample

The final analytic sample size was 7501, representing an estimated 5 750 000 children in the United States with a mental health condition potentially in need of care coordination. The majority of the children were male (67.4%),

aged 12 to 17 years (53.7%), and white (61.5%) (Table 1). Of the 4 mental health conditions, ADHD was the most common (67.4%), followed by conduct disorder (33.6%), anxiety disorder (31.2%), and depression (21.3%). Nearly one-third (31.9%) of children had a physical health condition, and 7.2% were on the autism spectrum. Nearly one-third of respondents reported family stress (31.6%), and the majority of respondents felt as though they had social support (83.0%). More than one-half of all parents had less than a high school education. More than one-half of our sample (57.2%) reported receipt of family-centered care.

Need and Unmet Need for Care Coordination

The prevalence of need for care coordination was 43.2% (Table 2), including 21.9% with met need and 18.7% with unmet need. Among those with need, the prevalence of unmet need for care coordination was 41.2%.

Correlates of Need for Care Coordination

In the bivariate analysis, children with anxiety disorder (unadjusted relative risk [RR]: 1.37 [95% confidence interval (CI): 1.19–1.55]), conduct disorder (unadjusted RR: 1.39 [95% CI: 1.21–1.57]), depression (unadjusted RR: 1.30 [95% CI: 1.11–1.49]), a physical health condition (unadjusted RR: 1.25 [95% CI: 1.10–1.39]), or autism (unadjusted RR: 1.24 [95% CI: 1.04–1.44]) were at higher risk of having a need for care coordination compared with children in our sample without these conditions (Table 3). Respondents who reported ≥ 1 type of family stress also had a higher risk of needing care coordination (unadjusted RR: 1.40 [95% CI: 1.21–1.58]). Those who received social support had a lower risk of needing care coordination (RR: 0.75 [95% CI: 0.63–0.87]).

In the adjusted model, those with anxiety disorder, conduct disorder, a physical health condition, and autism remained at higher risk of need for care coordination (Table 3). Sociodemographic variables found to be associated with higher risk of need for care coordination after adjustment were black race and respondents who reported that the child's father had less than a high school education.

Correlates of Unmet Need for Care Coordination

In bivariate analyses of correlates of unmet need for care coordination among children of respondents reporting a need, those with anxiety disorder (unadjusted RR: 1.33 [95% CI: 1.04–1.62]), conduct disorder (unadjusted RR: 1.41 [95% CI: 1.09–1.72]), and autism (unadjusted RR: 1.46 [95% CI: 1.01–1.90]) had a higher risk of unmet need. In the adjusted analyses, only those with anxiety disorder remained at higher risk of unmet need for care coordination (Table 3).

Respondents with family stress had a higher risk of unmet need (unadjusted RR: 1.47 [95% CI: 1.15–1.79]) in unadjusted analyses, but the association was not statistically significant in adjusted analyses. Those who reported having social support (RR: 0.59 [95% CI: 0.46–0.74]) and receipt of family-centered care (RR: 0.63 [95% CI: 0.55–0.72]) had a statistically significantly lower risk of unmet need; this association persisted after adjustment.

Sociodemographic variables associated with statistically significantly higher risk of unmet need for care coordination in adjusted analyses included income level between 200% and 299% of the federal poverty level, public insurance, and being uninsured.

DISCUSSION

Our national study representing >5 million children with a mental health condition demonstrated that among

TABLE 1 Description of the Sample

Characteristic	N	Weighted %
All participants	7501	100.0
Gender		
Male	4807	67.4
Female	2688	32.6
Age, y		
2–5	331	6.0
6–11	2628	40.3
12–17	4542	53.7
Race/ethnicity		
White, non-Hispanic	5339	61.5
Black, non-Hispanic	738	16.5
Hispanic	706	14.5
Multiracial	406	5.4
Other	211	2.1
Household income		
$\leq 199\%$ FPL	2331	47.6
200%–299% FPL	963	15.9
300%–399% FPL	1279	10.8
$\geq 400\%$ FPL	2441	25.6
Insurance status		
Private	4462	51.3
Public	2638	44.1
Uninsured	328	4.6
Family structure		
Two parents	4651	56.0
Single mother	1939	32.8
Other	873	11.2
Primary language		
English	7296	94.5
Non-English	201	5.5
Mental health condition		
ADHD	5100	67.4
Anxiety disorder	2540	31.2
Conduct disorder	2188	33.6
Depression	1596	21.3
Other health condition		
Physical health condition	2142	31.9
Autism	501	7.2
Maternal mental health		
Excellent	1374	19.7
Very good	2527	32.9
Good	1775	26.8
Fair	799	16.6
Poor	190	4.0
Paternal mental health		
Excellent	1301	26.1
Very good	2048	41.2
Good	1090	22.6
Fair	400	8.5
Poor	80	1.6
Family stress		
Yes	2105	31.6
Social support		
Yes	6468	83.0
Maternal education		
>High school	568	12.9
High school	1504	28.9
<High school	4576	58.2
Paternal education		
>High school	420	11.6
High school	1270	31.5
<High school	3208	56.8

TABLE 1 Continued

Characteristic	N	Weighted %
Family-centered care		
Yes	4863	57.2

Values presented as weighted percentages may not sum to 100% due to rounding, and numbers may not sum to total due to missing data. FPL, federal poverty level.

parents of children who need care coordination, 41% have an unmet need. In addition, we found that children with anxiety disorder, those who are publicly insured, and those who are uninsured experience the greatest risk of having an unmet need for care coordination. Finally, we found that lower unmet need for care coordination was associated with receipt of social support and family-centered care.

Previous work examining care coordination in pediatric populations found that nearly one-third of children with special health care needs have an unmet need for care coordination.¹⁷ Although the literature supports strengthening care coordination for children with special health care needs more generally, our findings show that care coordination may need to be targeted to more specific subpopulations of children with mental health conditions who have highest unmet need, such as those with anxiety disorders. Anxiety disorders are among the earliest disorders to present in children.²⁷ They are frequently associated with somatic complaints (eg, abdominal pain, chest discomfort, headaches) in the pediatric population, and primary care providers may focus on managing such symptoms, resulting in a delayed diagnosis of the underlying anxiety disorder.²⁸ High rates of emergency department use and subspecialty care

among children with anxiety disorders may, in part, explain the association with perceived need for care coordination and their higher risk of unmet care coordination need.²⁹ Increased recognition of anxiety disorders and awareness of evidence-based treatment approaches by pediatric providers may lead to improved management and better coordination of care.²⁹

We did not find an association between need and unmet need for care coordination among children in our sample with ADHD, which may in part be explained by a higher comfort level with ADHD management in the pediatric primary care setting.³⁰ However, other studies have found that primary care providers believe that better care coordination is needed for children with ADHD, particularly regarding collaboration with schools, educating families, and facilitating mental health care.³¹ Further research is needed to better understand pediatric providers' perceptions of care coordination needs among children with ADHD.

Parents who reported experiencing ≥ 1 type of parenting stress were at higher risk of reporting need and unmet need for care coordination, although this association was not significant in adjusted analyses. This finding agrees in part with a previous study by Antonelli et al.¹⁰ The authors found a high prevalence of care coordination minutes used both by children with special health care needs and children without special health care needs who presented with an acute, family-based social stressor. Parental stress has been shown to be a barrier to seeking

mental health and community support services for children with behavior problems.³² Primary care providers and other care coordinators should identify psychosocial stressors among children with mental health conditions because children who experience stressors are at higher risk for having unmet need for care coordination and potentially nonreceipt of services.

Preventing unmet need for care coordination among children with mental health conditions may hinge, in part, on identifying family- and system-level attributes that keep families engaged in care and help them navigate different systems of care. Our findings showing lower unmet need for care coordination among respondents who report receipt of social support and family-centered care suggest 2 potential strategies to improve parent experiences with care coordination for children with mental health conditions. Studies have shown that patients who report having social support have higher levels of trust in the health care system, are more engaged in care, and have better self-rated health compared with patients who do not have sources of social support.³³ Parents of children with special health care needs who receive family-centered care report better family-provider communication and perceptions of partnership, which are foundational to optimizing care coordination.³⁴ Our analysis focused on predisposing, enabling, and need factors that may influence parent perceptions of need and unmet need for care coordination. Further research should explore parent perceptions of access to care among children with mental health conditions, as well as the impact of perceived access on parent perceptions of care coordination.

Several limitations of our analysis should be acknowledged. First, care coordination questions were asked only of parents who reported use of ≥ 2

TABLE 2 Prevalence of Need for Care Coordination Among Children With Mental Health Conditions

Care Coordination Need Category	Weighted % (95% CI)
Any need for care coordination	43.2 (40.3–46.1)
Unmet need	18.7 (15.6–20.1)
Met need	21.9 (22.7–28.0)
No need	59.4 (57.0–62)
Among those with any need, proportion of unmet need	41.2 (36.7–45.8)

TABLE 3 Association Between Independent Variables and Unadjusted and Adjusted Risk of Need and Unmet Need for Care Coordination

Variable	Need Care Coordination (n = 2871)		Unmet Need for Care Coordination Among Those With Need (n = 1132)	
	Unadjusted RR	Adjusted RR	Unadjusted RR	Adjusted RR
ADHD				
Yes	0.88 (0.75 to 1.00)	1.07 (0.94 to 1.20)	0.85 (0.67 to 1.04)	0.97 (0.79 to 1.15)
No	Ref	Ref	Ref	Ref
Anxiety disorder				
Yes	1.37*** (1.19 to 1.55)	1.28*** (1.13 to 1.43)	1.33* (1.04 to 1.62)	1.31** (1.09 to 1.53)
No	Ref	Ref	Ref	Ref
Conduct disorder				
Yes	1.39*** (1.21 to 1.57)	1.19* (1.04 to 1.34)	1.41* (1.10 to 1.72)	1.12 (0.92 to 1.32)
No	Ref	Ref	Ref	Ref
Depression				
Yes	1.30** (1.11 to 1.49)	1.16 (0.98 to 1.33)	1.09 (0.84 to 1.33)	0.89 (0.70 to 1.09)
No	Ref	Ref	Ref	Ref
Physical health condition				
Yes	1.41*** (1.22 to 1.60)	1.25*** (1.10 to 1.39)	0.97 (0.75 to 1.18)	0.92 (0.76 to 1.08)
No	Ref	Ref	Ref	Ref
Autism				
Yes	1.51*** (1.25 to 1.77)	1.24* (1.04 to 1.44)	1.46* (1.01 to 1.90)	1.15 (0.86 to 1.45)
No	Ref	Ref	Ref	Ref
Maternal mental health, excellent				
Ref	Ref	Ref	Ref	Ref
Very good	1.12 (0.85 to 1.39)	0.99 (0.77 to 1.20)	1.05 (0.59 to 1.51)	0.98 (0.63 to 1.32)
Good	1.45** (1.11 to 1.78)	1.15 (0.89 to 1.40)	1.45 (0.86 to 2.04)	1.14 (0.76 to 1.53)
Fair	1.72*** (1.30 to 2.13)	1.27 (0.95 to 1.59)	1.43 (0.78 to 2.07)	1.01 (0.61 to 1.42)
Poor	1.50 (0.93 to 2.07)	0.98 (0.60 to 1.36)	1.43 (0.64 to 2.22)	0.82 (0.39 to 1.24)
Paternal mental health, excellent				
Ref	Ref	Ref	Ref	Ref
Very good	1.27 (0.95 to 1.59)	1.21 (0.94 to 1.50)	1.27 (0.64 to 1.90)	1.13 (0.62 to 1.64)
Good	1.49* (1.11 to 1.87)	1.27 (0.97 to 1.57)	1.24 (0.63 to 1.86)	0.99 (0.57 to 1.42)
Fair	1.59* (1.14 to 2.04)	1.02 (0.74 to 1.31)	1.80 (0.92 to 2.70)	0.99 (0.49 to 1.48)
Poor	2.18** (1.40 to 2.96)	1.50 (0.99 to 2.01)	1.11 (−0.0085 to 2.23)	0.61 (−0.032 to 1.25)
Family stress	1.40*** (1.21 to 1.58)	1.13 (0.99 to 1.27)	1.47** (1.15 to 1.79)	1.19 (0.99 to 1.39)
Social support	0.75*** (0.63 to 0.87)	0.87* (0.74 to 0.99)	0.60*** (0.46 to 0.74)	0.69*** (0.55 to 0.83)
Maternal education, >high school				
Ref	Ref	Ref	Ref	Ref
High school	0.99 (0.84 to 1.15)	0.87* (0.75 to 0.99)	1.18 (0.87 to 1.48)	0.88 (0.68 to 1.08)
<High school	1.01 (0.74 to 1.27)	0.72** (0.54 to 0.90)	1.20 (0.78 to 1.62)	0.91 (0.63 to 1.19)
Paternal education, >high school				
Ref	Ref	Ref	Ref	Ref
High school	1.06 (0.85 to 1.27)	1.06 (0.91 to 1.22)	1.25 (0.83 to 1.67)	1.13 (0.87 to 1.39)
<High school	1.40* (1.09 to 1.72)	1.28* (1.01 to 1.55)	1.57 (0.93 to 2.21)	1.10 (0.76 to 1.45)
Age				
2–5 y	Ref	Ref	Ref	Ref
6–11 y	0.78 (0.56 to 1.00)	0.85 (0.64 to 1.06)	0.91 (0.59 to 1.23)	0.99 (0.65 to 1.33)
12–17 y	0.79 (0.57 to 1.01)	0.89 (0.66 to 1.12)	0.91 (0.59 to 1.22)	1.04 (0.67 to 1.41)
Race				
White, non-Hispanic	Ref	Ref	Ref	Ref
Black, non-Hispanic	1.28* (1.06 to 1.50)	1.22* (1.02 to 1.42)	1.11 (0.80 to 1.42)	0.97 (0.71 to 1.23)
Hispanic	1.37* (1.07 to 1.66)	1.09 (0.85 to 1.34)	1.14 (0.78 to 1.51)	0.95 (0.62 to 1.28)
Multiracial	1.19 (0.89 to 1.49)	1.12 (0.90 to 1.34)	0.76 (0.43 to 1.09)	0.73* (0.49 to 0.97)
Other	1.22 (0.88 to 1.56)	1.07 (0.75 to 1.39)	1.31 (0.85 to 1.78)	1.11 (0.75 to 1.47)
Income				
≥400% FPL	Ref	Ref	Ref	Ref
300%–399% FPL	0.79* (0.63 to 0.98)	0.80** (0.66 to 0.95)	1.77* (1.13 to 2.41)	1.33 (0.98 to 1.67)
200%–299% FPL	1.072 (0.85 to 1.29)	0.971 (0.82 to 1.12)	1.85* (1.16 to 2.54)	1.35* (1.00 to 1.69)
≤199% FPL	1.07 (0.88 to 1.27)	0.89 (0.75 to 1.03)	1.73* (1.16 to 2.31)	1.04 (0.72 to 1.35)
Insurance status				
Private	Ref	Ref	Ref	Ref
Public	1.15 (0.99 to 1.31)	0.99 (0.86 to 1.14)	1.42* (1.10 to 1.74)	1.38* (1.05 to 1.72)
Uninsured	1.20 (0.90 to 1.49)	1.08 (0.84 to 1.33)	2.05*** (1.45 to 2.65)	1.86** (1.25 to 2.5)
Family structure				
Two parents	Ref	Ref	Ref	Ref
Single mother	1.09 (0.93 to 1.26)	1.20 (0.76 to 1.63)	1.21 (0.92 to 1.50)	0.79 (0.42 to 1.17)
Other	1.11 (0.89 to 1.33)	1.25 (0.78 to 1.71)	0.83 (0.55 to 1.11)	0.68 (0.16 to 1.19)

TABLE 3 Continued

Variable	Need Care Coordination (n = 2871)		Unmet Need for Care Coordination Among Those With Need (n = 1132)	
	Unadjusted RR	Adjusted RR	Unadjusted RR	Adjusted RR
Primary language				
Non-English	1.33 (0.83 to 1.82)	0.89 (0.51 to 1.26)	1.33 (0.84 to 1.82)	1.08 (0.58 to 1.56)
Health care characteristic				
Family-centered care	0.63*** (0.55 to 0.72)	0.72*** (0.64 to 0.83)	0.39*** (0.29 to 0.48)	0.43*** (0.35 to 0.52)

FPL, federal poverty level.

* $P < .05$, ** $P < .01$, *** $P < .001$.

health services, defined broadly as preventive medical care, dental care, mental health care, or subspecialty care. We did not restrict our sample to children with mental health conditions who used specific combinations of these clinical services; therefore, children in our sample who may have only used preventive medical care and dental care were included in our analysis. Because these 2 services do not traditionally fall within the realm of requiring care coordination resources, it is unclear what parental perceptions of need and unmet need for care coordination mean in such cases. Further research exploring need and unmet need for care coordination for preventive and dental care services is needed. In addition, children with mental health conditions who use services that fall outside of the traditional health care system (eg, early intervention services, school-based interventions) may also require care coordination, yet they were not included in our sample. Hence, the numbers of children needing care coordination services may have been underestimated. Second, mental health diagnoses were based exclusively on

parent report with no validation of that diagnosis. Misclassification bias may have been introduced if parents failed to recognize that their child had a mental health condition or that their child needed care coordination. Conversely, parents may overreport their children's mental health diagnoses, particularly parents with an underlying mental health disorder.^{36,37} Third, our analysis did not account for comorbid mental health conditions or disease severity and may thus underestimate populations at risk for high need and unmet need for care coordination. Finally, the cross-sectional design of the data source precludes inferring causality.

Pediatricians are often the first to see children with mental health conditions; they often feel ill-equipped to not only care for such patients but also identify specialists and community-based resources that can help facilitate a coordinated system of care.¹⁵ In addition, pediatric providers cite lack of time, inadequate reimbursement, and lack of staff as reasons for limited provision of care coordination.⁹ Our results may be helpful to pediatric providers and

policymakers who seek to better understand which specific subpopulations of children with special health care needs may benefit most from care coordination, thus helping them better target time and resources devoted to care coordination activities. Also, our findings elucidate parent psychosocial characteristics that may inform satisfaction with care coordination services, which will be important to those developing care coordination quality measures.

CONCLUSIONS

Our study identified that level of unmet need for care coordination among children with mental health conditions is high, particularly among children diagnosed with anxiety disorder. Fortunately, our study identified both social support and family-centered care as protective factors. Designing and implementing interventions that identify and enhance family-based supports, as well as those that seek to strengthen family-centered care, may help to reduce unmet need for care coordination in this vulnerable population.

REFERENCES

- Connor DF, McLaughlin TJ, Jeffers-Terry M, et al. Targeted child psychiatric services: a new model of pediatric primary clinician—child psychiatry collaborative care. *Clin Pediatr (Phila)*. 2006;45(5):423–434
- Costello EJ, Egger H, Angold A. 10-year research update review: the epidemiology of child and adolescent psychiatric disorders: I. Methods and public health burden. *J Am Acad Child Adolesc Psychiatry*. 2005;44(10):972–986
- Grimes KE, Kapunan PE, Mullin B. Children's health services in a "system of care": patterns of mental health, primary and specialty use. *Public Health Rep*. 2006;121(3):311–323

4. O'Connell ME, Boat T, Warner KE, eds. *Preventing Mental, Emotional, and Behavioral Disorders Among Young People*. Washington, DC: National Academies Press; 2009
5. Suter JC, Bruns EJ. Effectiveness of the wraparound process for children with emotional and behavioral disorders: a meta-analysis. *Clin Child Fam Psychol Rev*. 2009;12(4):336–351
6. Patient Protection and Affordable Care Act, 124 Stat 111–148, HR 3590, Sec 2703 (2010)
7. SAMHSA-HRSA, Center for Integrated Health Solutions. Behavioral health homes for people with mental health and substance abuse conditions. Available at: www.integration.samhsa.gov/clinical-practice/CIH-S_Health_Homes_Core_Clinical_Features.pdf. Accessed July 12, 2012
8. Wise P, Huffman L, Brat G. *A Critical Analysis of Care Coordination Strategies for Children With Special Health Care Needs, Technical Review 14*. Prepared by the Stanford University-UCSF Evidence-based
9. American Academy of Pediatrics Council on Children with Disabilities. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. *Pediatrics*. 2005;116(5):1238–1244
10. Antonelli RC, Stille CJ, Antonelli DM. Care coordination for children and youth with special health care needs: a descriptive, multisite study of activities, personnel costs, and outcomes. *Pediatrics*. 2008;122(1). Available at: www.pediatrics.org/cgi/content/full/122/1/e209
11. McAllister JW, Presler E, Turchi RM, Antonelli RC. Achieving effective care coordination in the medical home [published correction appears in *Pediatr Ann*. 2009;38(12):636]. *Pediatr Ann*. 2009;38(9):491–497
12. Turchi RM, Berhane Z, Bethell C, Pomponio A, Antonelli R, Minkovitz CS. Care coordination for CSHCN: associations with family-provider relations and family/child outcomes. *Pediatrics*. 2009;124(suppl 4):S428–S434
13. Fisher ES, McClellan MB, Bertko J, et al. Fostering accountable health care: moving forward in Medicare. *Health Aff (Millwood)*. 2009;28(2):w219–w231
14. Shojania KG, McDonald KM, Wachter RM, et al. *Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies: Volume 7—Care Coordination* (Prepared by the Stanford University-UCSF Evidence-based Practice Center under contract 290-02-0017). Rockville, MD: Agency for Healthcare Research and Quality; June 2007. AHRQ publication 04(07)-0051-7
15. Palfrey JS, Sofis LA, Davidson EJ, Liu J, Freeman L, Ganz ML; Pediatric Alliance for Coordinated Care. The Pediatric Alliance for Coordinated Care: evaluation of a medical home model. *Pediatrics*. 2004;113(suppl 5):1507–1516
16. Institute of Medicine (US) Committee on Crossing the Quality Chasm. *Adaptation to Mental Health and Addictive Disorders. Improving the Quality of Health Care for Mental and Substance-Use Conditions: Quality Chasm Series*. Washington, DC: National Academies Press; 2006
17. Toomey SL, Chien AT, Elliott MN, Ratner J, Schuster MA. Disparities in unmet need for care coordination: the national survey of children's health. *Pediatrics*. 2013;131(2):217–224
18. Blumberg SJ, Foster EB, Frasier AM, et al. Design and operation of the National Survey of Children's Health, 2007. *Vital Health Stat 1*. 2012;(55):1–149
19. Child and Adolescent Health Measurement Initiative (CAHMI). Data resource Center for Child and Adolescent Health. Available at: www.childhealthdata.org. Accessed January 20, 2012
20. Ghandour RM, Perry DF, Kogan MD, Strickland BB. The medical home as a mediator of the relation between mental health symptoms and family burden among children with special health care needs. *Acad Pediatr*. 2011;11(2):161–169
21. Gelberg L, Andersen RM, Leake BD. The behavioral model for vulnerable populations: application to medical care use and outcomes for homeless people. *Health Serv Res*. 2000;34(6):1273–1302
22. Teagle SE. Parental problem recognition and child mental health service use. *Ment Health Serv Res*. 2002;4(4):257–266
23. Stille C, Turchi RM, Antonelli R, et al; Academic Pediatric Association Task Force on Family-Centered Medical Home. The family-centered medical home: specific considerations for child health research and policy. *Acad Pediatr*. 2010;10(4):211–217
24. Bourguignon F, Fournier M, Gurgand M. Selection bias corrections based on the multinomial logit model: Monte Carlo comparisons. *J Econ Surv*. 2007;21(1):174–205
25. Heckman JJ. Sample selection bias as a specification error. *Econometrica*. 1979;47(1):153–161
26. Kleinman LC, Norton EC. What's the risk? A simple approach for estimating adjusted risk measures from nonlinear models including logistic regression. *Health Serv Res*. 2009;44(1):288–302
27. Stata Corp. *Stata Statistical Software: Release 12* [computer program]. College Station, TX: Stata Corp LP; 2011
28. Beesdo K, Knappe S, Pine DS. Anxiety and anxiety disorders in children and adolescents: developmental issues and implications for DSM-V. *Psychiatr Clin North Am*. 2009;32(3):483–524
29. Ramsawh HJ, Chavira DA, Stein MB. Burden of anxiety disorders in pediatric medical settings: prevalence, phenomenology, and a research agenda. *Arch Pediatr Adolesc Med*. 2010;164(10):965–972
30. Richardson LP, Russo JE, Lozano P, McCauley E, Katon W. The effect of comorbid anxiety and depressive disorders on health care utilization and costs among adolescents with asthma. *Gen Hosp Psychiatry*. 2008;30(5):398–406
31. Power TJ, Mautone JA, Manz PH, Frye L, Blum NJ. Managing attention-deficit/hyperactivity disorder in primary care: a systematic analysis of roles and challenges. *Pediatrics*. 2008;121(1). Available at: www.pediatrics.org/cgi/content/full/121/1/e65
32. Stein RE, Horwitz SM, Storfer-Isser A, Heneghan A, Olson L, Hoagwood KE. Do pediatricians think they are responsible for identification and management of child mental health problems? Results of the AAP periodic survey. *Ambul Pediatr*. 2008;8(1):11–17
33. Floyd FF, Gallagher EM. Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Fam Relat*. 1997;46(4):359–371
34. Shier G, Ginsburg M, Howell J, Volland P, Golden R. Strong social support services, such as transportation and help for caregivers, can lead to lower health care use and costs. *Health Aff (Millwood)*. 2013;32(3):544–551
35. Kuhlthau KA, Bloom S, Van Cleave J, et al. Evidence for family-centered care for children with special health care needs: a systematic review. *Acad Pediatr*. 2011;11(2):136–143
36. Youngblade LM, Shenkman EA. Congruence between parents' and adolescents' reports of special health care needs in a Title XXI program. *J Pediatr Psychol*. 2003;28(6):393–401
37. Seiffge-Krenke I, Kollmar F. Discrepancies between mothers' and fathers' perceptions of sons' and daughters' problem behaviour: a longitudinal analysis of parent-adolescent agreement on internalising and externalising problem behaviour. *J Child Psychol Psychiatry*. 1998;39(5):687–697

Need and Unmet Need for Care Coordination Among Children With Mental Health Conditions

Nicole M. Brown, Jeremy C. Green, Mayur M. Desai, Carol C. Weitzman and Marjorie S. Rosenthal

Pediatrics 2014;133:e530

DOI: 10.1542/peds.2013-2590 originally published online February 17, 2014;

Updated Information & Services

including high resolution figures, can be found at:
<http://pediatrics.aappublications.org/content/133/3/e530>

References

This article cites 28 articles, 7 of which you can access for free at:
<http://pediatrics.aappublications.org/content/133/3/e530#BIBL>

Subspecialty Collections

This article, along with others on similar topics, appears in the following collection(s):

Community Pediatrics

http://www.aappublications.org/cgi/collection/community_pediatrics_sub

Medical Home

http://www.aappublications.org/cgi/collection/medical_home_sub

Developmental/Behavioral Pediatrics

http://www.aappublications.org/cgi/collection/development:behavioral_issues_sub

Psychosocial Issues

http://www.aappublications.org/cgi/collection/psychosocial_issues_sub

Permissions & Licensing

Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:
<http://www.aappublications.org/site/misc/Permissions.xhtml>

Reprints

Information about ordering reprints can be found online:
<http://www.aappublications.org/site/misc/reprints.xhtml>

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Need and Unmet Need for Care Coordination Among Children With Mental Health Conditions

Nicole M. Brown, Jeremy C. Green, Mayur M. Desai, Carol C. Weitzman and Marjorie S. Rosenthal

Pediatrics 2014;133:e530

DOI: 10.1542/peds.2013-2590 originally published online February 17, 2014;

The online version of this article, along with updated information and services, is located on the World Wide Web at:

<http://pediatrics.aappublications.org/content/133/3/e530>

Pediatrics is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. Pediatrics is owned, published, and trademarked by the American Academy of Pediatrics, 345 Park Avenue, Itasca, Illinois, 60143. Copyright © 2014 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

