

Unmet Need for Routine and Specialty Care: Data From the National Survey of Children With Special Health Care Needs

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ABSTRACT. *Objective.* To assess the prevalence of unmet needs for routine and specialty care among children with special health care needs (CSHCN) and to identify factors associated with the likelihood of having unmet need for medical care.

Methods. Data come from the respondents for 38 866 children interviewed for the National Survey of Children With Special Health Care Needs. Bivariate analyses were used to assess differences in unmet need for medical care by various environmental, predisposing, enabling, and need factors. Logit analyses were used to determine independent effects of these variables on the likelihood of having an unmet need for medical care.

Results. Nationally, 74.4% and 51.0% of CSHCN needed routine and subspecialty physician care, respectively. Of those reporting that they needed routine care, 3.2% were unable to obtain these services. Of those reporting a need for specialty care, 7.2% reported not obtaining all needed specialty care. The prevalence of unmet need for specialty care significantly exceeded the prevalence of unmet need for routine care. In logit analyses, African American children and children whose mothers had less than a high-school education faced twice the odds of having an unmet need for routine care. Compared with nonpoor children, children living below the federal poverty level were significantly more likely to have an unmet need for routine (adjusted odds ratio [aOR]: 1.97; 95% confidence interval [CI]: 1.23–3.14) and specialty (aOR: 2.50; 95% CI: 1.49–4.18) care. Near-poor children were also significantly more likely than nonpoor children to have unmet needs for routine and specialty care. Uninsured children were significantly more likely than continuously insured children to report an unmet need for routine (aOR: 7.51; 95% CI: 4.99–11.30) and specialty (aOR: 4.29; 95% CI: 2.99–6.15) care. Our findings also show that higher levels of general pediatrician supply, relative to the pediatric population, are associated with a significantly lower likelihood of having an unmet need for routine care. Likewise, a greater supply of pediatric subspecialists is associated with a decreased likelihood of having an unmet need for specialty care.

Conclusions. Compared with previous reports of the general pediatric population, CSHCN have higher levels of unmet need for medical services. Our regression results emphasize that children vulnerable because of their social circumstances (eg, poverty, etc) have significantly

greater odds of having unmet need for routine and specialty physician care. Furthermore, our findings highlight the importance of insurance coverage in ensuring access to needed routine and specialty medical services. *Pediatrics* 2004;113:e109–e115. URL: <http://www.pediatrics.org/cgi/content/full/113/2/e109>; children, chronic conditions, special health care needs, access to care, utilization.

ABBREVIATIONS. CSHCN, children with special health care needs; MSA, metropolitan statistical area; SCHIP, State Children's Health Insurance Program; OR, odds ratio.

Unmet need for health services is a construct used to capture the degree to which needed health services are not received.¹ For example, an inability to see a provider for routine immunizations would represent an unmet need for routine medical care. Although several studies have explored unmet need for medical care among the general pediatric population,^{1–3} few have examined this issue among children with special health care needs (CSHCN).⁴ CSHCN, as defined by the Maternal Child Health Bureau,⁵ comprise 15%–20% of the <18 population in the United States.^{2,4,6} One should note that, although the Maternal Child Health Bureau definition of CSHCN includes children who are at risk, prevalence estimates based on survey data generally include only children with existing special health care needs. This substantial minority of children may account for a large percentage of the pediatric population's health care expenditures.^{7,8} Despite the nonnegligible size of the population of CSHCN and, by definition, their potential for having considerable need for health care services, we know little about the extent to which these children have unmet needs for routine and specialty physician care.

Previous studies of the general pediatric population (ie, healthy and ill children combined) have found that the prevalence of unmet health needs, often broadly defined as having any unmet need, in this population tends to be <10%. Newacheck et al¹ found that 7.3% of children in the 1993–1996 National Health Interview Survey reported having an unmet need for dental or medical care, eyeglasses, or prescriptions. Approximately 1.6% of children in the United States were estimated to have an unmet need specifically for medical services. Having any unmet need for health care was positively associated with being poor or near poor, uninsured, in fair or poor health, and younger. In a similar study, the preva-

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lence of having an unmet need for primary care was lowest among nonpoor, privately insured children (0.6%) and highest among uninsured children (5.9%).³ The prevalence of unmet need among children covered by Medicaid was midway between the two at 2.1%.

Using the 1994 National Health Interview Survey, Newacheck et al⁴ also analyzed unmet needs for services among the subpopulation of children with existing special health care needs. They found that 18% of the under-18 population had an existing special health care need and, of those, 12.2% reported having ≥ 1 unmet needs for health care (dental care, medical care, mental health services, prescriptions, and/or eyeglasses), and 3.2% had an unmet need for medical care specifically. These data suggest that unmet need for health care services may be twice as high among CSHCN than it is among the general under-18 population.

Because of the relatively low incidence of chronic conditions among children, national surveys make it difficult to obtain detailed information on CSHCN. In an effort to rectify this situation and provide detailed information on CSHCN, the Maternal and Child Health Bureau of the Health Resources and Services Administration and the Office of the Assistant Secretary for Planning and Evaluation of the Department of Health and Human Services sponsored the National Survey of Children With Special Health Care Needs.⁹ This survey assesses need for a variety of medical care services such as routine physician care, mental health services, etc. Respondents first were asked whether the sample child needed the service. For those who responded that the service was needed, respondents then were asked whether the child received the needed service. Thus, in contrast to previous surveys in which all children were asked whether they were unable to obtain a service regardless of their need for the service, the National Survey of Children With Special Health Care Needs allows exploration of unmet need among the population of children with a perceived need for the service.

We used the National Survey of Children With Special Health Care Needs to perform national-level analyses of receipt of needed routine and specialty care among a recent, nationally representative sample of CSHCN. In contrast to previous studies that examined access to "medical care" as 1 class of services, we examine the prevalence of unmet need for routine and specialty physician services separately. We also use logistic regression analyses to explore the extent to which the risk of unmet need in CSHCN is associated with such factors as demographic characteristics, insurance status, and physician supply.

METHODS

The National Survey of Children With Special Health Care Needs was conducted from April 2000 to October 2002 by using the State and Local Area Integrated Telephone Survey and includes a household file, a screener file, and an interview file.⁹ The screener interview was used to identify 750 children with existing special health care needs in each state and the District of Columbia except Missouri, which elected to sample 1500 children. In total, 372 174 screener interviews took place, and 38 866 interviews of

CSHCN were completed. Detailed information on the National Survey of Children With Special Health Care Needs is published elsewhere¹⁰ For our study we used data from all 3 files: the screener file contained data on race and ethnicity; the household file included state of residence, metropolitan status, and household income relative to poverty; and the interview file contained most of our variables of interest, such as the child's age, gender, and mother's educational attainment, severity of the child's condition, and insurance status. The National Survey of Children With Special Health Care Needs estimates that 12.8% of children in the United States had a special health care need.¹⁰

Our dependent variables of interest were reported unmet needs for routine and specialty physician services. During the interview, respondents (parents in >95% of interviews) were asked whether their child needed routine preventive care in the previous 12 months. Those respondents who answered affirmatively then were asked whether their child had received all needed routine preventive care. Identical questions were asked about specialty physician services. Children whose parents reported that they did not receive needed routine care were classified as having an unmet need for routine care. Likewise, children whose respondent reported that the child did not receive needed specialty care were considered to have an unmet need for specialty care.

To guide the formation of our regression model, we used the Behavioral Model of Health Services Use as a conceptual framework. This model asserts that health care utilization is a function of predisposing, enabling, need, and environmental factors.¹¹ We included gender, race, ethnicity, and maternal education as predisposing characteristics. The National Survey of Children With Special Health Care Needs included separate questions on race and ethnicity; we elected to keep these 2 variables separate in analyses to explore their individual associations with unmet need. Enabling factors included usual source of care setting, insurance status, and family poverty status. Age and severity and stability of the child's condition were included as need factors. Our categorization of age took an approach intended to capture developmental stages as well as typical utilization of health care. For example, we separate infants from 1- to 5-year-olds because of their frequent immunizations and well-child visits. We elected to separate 10- to 12-year-olds from adolescents because the age at which children transition to adult care is not well established. Residence in a metropolitan statistical area (MSA) and measures of physician supply were included as environmental factors.

Children who lacked insurance at any point in the previous year were classified as uninsured, because these children are at risk for having unmet needs during their gaps in insurance. Children who were insured for the entire previous 12 months were classified into 1 of the following insurance categories: private insurance, Medicaid, a State Children's Health Insurance Program (SCHIP), and other insurance. For children who were reported as having >1 form of insurance over the previous 12 months, we classified them into 1 group based on the following hierarchy: private insurance, Medicaid, SCHIP, or other. For example, a child with both private insurance and Medicaid was categorized as having private insurance. This allowed for direct comparisons of each insurance category to the other categories.

Two questions are used to control for health condition. Respondents were asked to rank the severity of the sample child's illness on a 0-to-10 scale, with 10 being the most severe. Because β coefficients across some ranks did not differ significantly, we collapsed this variable into 4 severity categories by grouping adjacent ranks with statistically similar coefficients. Second, respondents were asked to describe the stability of the sample child's medical needs as "change all the time," "change only once in a while," "are usually stable," and "none of the above." We used these 4 categories to capture stability.

The National Center for Health Statistics suppressed metropolitan status in 16 states with small nonmetropolitan-statistical-area and/or metropolitan-statistical-area populations to protect confidentiality. As recommended by the National Center for Health Statistics, we recoded metropolitan status for these states as follows: from missing to nonmetropolitan for residents of states with small metropolitan samples (AK, ID, ME, MT, ND, SD, VT, and WY) and from missing to metropolitan for residents of states with small rural samples (CT, DE, HI, MA, MD, NH, NV, and RI). The reclassification results in misclassification of metropolitan status for only a small number of cases and allows inclusion of all respondents in our analysis (S. Blumberg, PhD, written commu-

nication, March 7, 2003). For all other variables, values labeled as “refused” or “don’t know” were recoded as missing. This reclassification affected only a small number of observations (<0.5%) for each variable.

To capture provider supply, we used aggregated population and provider licensure data from the 2002 Bureau of Health Professions Area Resource File¹² to create physician/population ratios. Physician data on the 2002 Area Resource File come from the 2000 Physician Masterfile. These include 2 measures of pediatric provider supply: the number of pediatricians per 10 000 people < 18 and the number of pediatric subspecialists per 10 000 people < 18. Because we expected the supply of general pediatricians to be potentially relevant to receipt of specialty care due to referral patterns, we entered this variable into both logit estimations. We also created a ratio of the number of internist subspecialists per 1000 people for inclusion in the analysis of unmet need for specialty care, because these providers may substitute for pediatric subspecialists in areas in which these providers are not available. For each provider supply variable, within each state the ratio was constructed for metropolitan counties and nonmetropolitan counties separately. Each child in the sample was assigned the ratio for their state and metropolitan status. For example, a child living in a rural Pennsylvania county was assigned the nonmetropolitan provider ratio for Pennsylvania, whereas a child living in a metropolitan area of Pennsylvania was assigned the metropolitan Pennsylvania ratios.

The design of the National Survey of Children With Special Health Care Needs allows the calculation of national-level estimates by using the population weights provided. To obtain correct variance estimates, all analyses must account for the survey design. We used STATA 7.0 (Stata Corporation, College Station, TX) to perform descriptive, bivariate, and logit analyses, using appropriate population weights and accounting for the survey design. Unless otherwise stated in the text, prevalence estimates presented are among children with a stated need for the service.

RESULTS

Characteristics of the study population are detailed in Table 1. Nationally, 74.4% and 51.0% of CSHCN needed routine and subspecialty physician care, respectively. Among all children surveyed, the prevalence of having an unmet need for routine or specialty care was 5.3%. Of those children whose parents reported a need for routine care, 3.2% were unable to obtain these services (Table 2). Of those reporting a need for specialty care, 7.3% reported not obtaining all needed specialty care. The prevalence of unmet need for specialty care significantly exceeded the prevalence of unmet need for routine care among those children reporting a need for physician services ($P < .001$). A number of variables including indicators of social vulnerability such as poverty and insurance status were significantly associated with having an unmet need for routine and/or specialty care in bivariate analyses. Although metropolitan residence alone was not significantly associated with having an unmet need for routine or specialty care in bivariate comparisons, lower levels of provider supply, a common characteristic of rural areas, were significantly associated with greater unmet need. Compared with children who reported receiving needed routine care, the general pediatrician/population ratio was significantly lower among children having an unmet need for routine services (6.71 vs 5.96; $P < .001$). Likewise, the pediatric subspecialist/population ratio was significantly lower among children with an unmet need for specialty services than among children receiving these services (1.32 vs 1.43; $P < .001$).

We performed logit analyses to assess the indepen-

TABLE 1. Population Estimates

	Percent (%) or Mean (SD)
Percent reporting a need for routine care	74.4
Percent reporting a need for specialty care	51.0
Environment	
Metropolitan residence	
Metropolitan residence	80.7
Nonmetropolitan residence	19.3
Predisposing	
Maternal education	
Less than high school	15.0
High school	30.2
More than high school	54.8
Gender	
Male	59.8
Female	40.2
Race	
White	75.1
African American	15.0
Multiracial	3.3
Other	6.6
Ethnicity	
Non-Hispanic	88.5
Hispanic	11.5
Age, y	
<1	1.3
1–4	13.5
5–9	29.3
10–12	22.5
13–18	33.4
Enabling	
Site of care	
Doctor’s office	72.7
Clinic	12.8
Other	14.4
Poverty status	
<100%	13.6
100%–199%	20.1
≥200%	66.3
Insurance status	
Ever uninsured during the previous 12 mos	11.6
Privately insured	68.9
Medicaid	17.1
Other	0.9
SCHIP	1.5
Need	
Severity rank	
Least severe (ranks 0–2)	30.2
Mildly severe	40.1
Modestly severe	24.2
Most severe	5.6
Stability	
Usually stable	6.6
Change once in a while	29.8
Change all the time	63.3
None of the above	0.2

SD indicates standard deviation.

dent effects of predisposing characteristics, enabling resources, need, and environmental factors on the likelihood of having an unmet need for routine and specialty care (Table 3). African American and multiracial children faced the odds of having an unmet need for routine care. Compared with children whose mothers had less than a high-school education, children whose mothers completed high school had half the odds of having an unmet need for routine care. Age, gender, and Hispanic ethnicity did not relate significantly to receipt of needed routine care.

Controlling for other factors, poor and near-poor

TABLE 2. Prevalence of Unmet Need for Routine and Specialty Care and Bivariate Results

	Unmet Need	
	Routine Care, %	Specialty Care, %
Total Number of CSHCN in United States with unmet need	221 235	343 519
Prevalence among CSHCN reporting a need for care	3.20	7.25
Bivariate results		
Environment		
Metropolitan residence		
Metropolitan residence	2.99	7.21
Nonmetropolitan residence	4.20	7.40
Ratio of general pediatricians to under-18 population		
Ratio of pediatric subspecialists to under-18 population		
Predisposing		
Maternal education		
Less than high school	8.05*	14.21*
High school	2.60	7.34
More than high school	2.46	5.86
Gender		
Male	3.17	7.55
Female	3.25	6.79
Race		
White	2.32*	6.49*
African American	5.40	8.92
Multiracial	6.04	11.74
Other	6.81	10.75
Ethnicity		
Non-Hispanic	2.93*	6.98
Hispanic	5.21	9.17
Age, y		
<1	8.40	4.13†
1–4	2.58	5.49
5–9	2.25	6.40
10–12	3.07	7.95
13–18	4.16	8.46
Enabling		
Site of care		
Doctor's office	2.17*	6.05*
Clinic	6.98	10.55
Other	5.51	10.44
Poverty status		
<100%	6.85*	16.09*
100%–199%	6.73	11.74
≥200%	1.55	4.45
Insurance status		
Ever uninsured during the previous 12 months‡	17.22*	23.39*
Privately insured	1.39*	4.34*
Medicaid‡	2.03†	9.38*
Other‡	4.48†	11.68*
SCHIP‡	1.62	6.85
Need		
Severity rank		
Least severe (ranks 0–2)	1.67*	2.63*
Mildly severe	2.63	6.40
Modestly severe	5.56	12.36
Most severe	5.05	7.95
Stability		
Usually stable	2.23*	5.08*
Change once in a while	4.59	8.56
Change all the time	5.89	15.06
None of the above	13.35	42.02

* $P < .01$.

† $P < .05$.

‡ Compared with private insurance.

children were significantly more likely to have an unmet need for routine care than nonpoor children were. Children who were uninsured at any time during the 12 months before the survey were also more likely than privately insured children to have an unmet need for routine care. Children who reported a doctor's office as their usual source of care were less likely than children with other usual

sources of care to report having an unmet need for routine care. Children with a moderately high severity ranking were significantly more likely than the least severely ill children to have an unmet need for routine care. It is important to note that our measure of general pediatrician supply also related significantly to children's receipt of routine services, with children residing in areas with greater supply of

TABLE 3. Survey Logit Models

Independent variables (referent group)	Did Not Receive All Needed Care			
	Routine		Specialty	
	OR	95% CI	OR	95% CI
Environment				
General pediatricians per 1000 population <18	0.90*	0.83–0.97	0.98	0.86–1.12
Pediatric subspecialist per 1000 population <18	—	—	0.63*	0.46–.86
Internist subspecialists per 1000 population <18	—	—	1.05	0.85–1.29
Metropolitan residence	1.22	0.71–2.09	2.26*	1.34–3.80
Predisposing				
Maternal education (less than high school)				
High school	0.51*	0.31–0.84	0.73	0.48–1.12
More than high school	0.69	0.42–1.14	0.82	0.56–1.19
Gender (female)				
Male	1.05	0.76–1.45	1.15	0.89–1.49
Race (white)				
African American	2.01*	1.32–3.06	.92	0.64–1.32
Multiracial	2.25†	1.19–4.26	1.46	0.80–2.67
Other	1.55	0.79–3.01	1.23	0.76–1.98
Ethnicity (non-Hispanic)				
Hispanic	0.84	0.43–1.64	0.65	0.42–1.01
Age (<1), y				
1–4	0.29	0.06–1.40	1.44	0.63–3.28
5–9	0.30	0.06–1.40	1.88	0.88–4.14
10–12	0.39	0.08–1.82	2.55†	1.15–5.61
13–18	0.59	0.13–2.68	2.79*	1.29–6.05
Enabling				
Site of care (other)				
Doctor's office	0.65†	0.45–0.95	0.85	0.63–1.14
Clinic	1.22	0.78–1.91	1.00	0.68–1.46
Poverty status (≥200% of federal poverty level)				
<100%	1.97*	1.23–3.14	2.50*	1.49–4.18
100%–199%	2.57*	1.70–3.89	1.93*	1.43–2.61
Insurance status (private)				
Ever uninsured during previous 12 mos	7.51*	4.99–11.30	4.29*	2.99–6.15
Medicaid	0.60	0.36–1.00	1.26	0.81–1.97
Other	2.01	0.57–7.12	1.67	0.76–3.67
SCHIP	0.52	0.19–1.41	0.82	0.40–1.70
Need				
Severity rank (least severe)				
Mildly severe	1.07	0.65–1.76	2.01*	1.42–2.86
Modestly severe	1.88†	1.13–3.13	3.22*	2.21–4.70
Most severe	1.39	0.75–2.58	1.49	0.90–2.48
Stability (usually stable)				
Change once in a while	1.31	0.90–1.90	1.37†	1.05–1.79
Change all the time	1.37	0.88–2.15	2.26*	1.51–1.3.39
None of the above	5.69*	1.74–18.64	6.99*	2.51–19.47

CI indicates confidence interval.

* $P < .01$.

† $P < .05$.

pediatricians being less likely to have an unmet need. Because an odds ratio (OR) is difficult to interpret for a continuous variable, we offer the following information. All other things equal, increase in the pediatrician/population ratio from the 10th percentile (1.9 physicians per 10 000 children) to the 90th percentile (10.6 physicians per 10 000 children) reduces the likelihood of an unmet need by 2.5 percentage points (from 4.2% to 1.7%).

Logit results for having an unmet need for specialty services differed somewhat from those for routine services. Maternal education and race did not relate significantly to having an unmet need for specialty care. The odds of having an unmet need for specialty care increased with children's age, however. Children aged 10 to 12 and 13 to 18 were significantly more likely to have an unmet need for specialty services than children <1.

As with routine care, poor and near-poor children

were significantly more likely than nonpoor children to have an unmet need for specialty care. Uninsured children were also more likely to have an unmet need for specialty care than privately insured children. There were no significant differences in reported unmet need between children with private insurance and those covered by public forms of insurance.

Compared with children with the lowest severity ranks, children with mild or moderate rankings were significantly more likely to have unmet needs for specialty care. Likewise, children whose needs were always or sometimes changing had significantly higher odds of having an unmet need than children with stable needs. Once again, we find that children whose stability was reported as "none of the above" were more likely to report having an unmet need for care.

Compared with their nonmetropolitan counter-

parts, children from metropolitan areas were significantly more likely to have an unmet need for specialty care. Although general pediatrician and internist specialists supply did not relate significantly to having an unmet need for specialty care, increased availability of pediatric subspecialists relative to the pediatric population significantly decreased the likelihood of children having an unmet need. All other things equal, a decrease in the pediatric subspecialist ratio from the 90th percentile (2.6 physicians per 10 000 children) to the 10th percentile (0.1 physicians per 10 000 children) triples the predicted probability that a child would have an unmet need for specialty care.

DISCUSSION

Our findings raise a number of important issues. First, it is surprising that only 74.4% of the parents in the study reported a need for routine care for their children. One would expect higher levels of need for routine care among this population of children. Given the substantial minority of children reporting an unmet need for routine and/or specialty care, our findings raise concerns that members of this already-vulnerable patient population may not be receiving necessary physician services.

The percentage of CSHCN with a perceived need for specialist care greatly exceeds that reported previously among the general pediatric population in MEPS (53% vs 18%).⁷ In addition, our investigation also shows that the percentage of CSHCN having an unmet need for subspecialty care exceeds the percentage of CSHCN with an unmet need for routine care. Thus, having an unmet need for specialty care is a more frequent occurrence than having an unmet need for routine care in this population. Previous research in this area is sparse, and it remains unclear whether access to pediatric subspecialty care in the United States is adequate. The Medicaid-claims-based analyses by Kuhlthau et al¹³ found that children with a variety of different chronic conditions relied heavily on generalists for their medical care. In contrast, a study comparing receipt of subspecialty care between privately insured children in the United States and all children in the United Kingdom found that US children use medical specialists at 2 times the rate of children from the United Kingdom and that 1 in 5 US children used specialty care.¹⁴ More research is needed to evaluate the adequacy of specialty care receipt among CSHCN and to monitor trends in the availability of this care.

Severity of illness has a surprising relationship with having an unmet need for care. Although one would hope that sicker children were less likely to have an unmet need for services, we found that children whose parents ranked them in mild or moderate ranges were significantly more likely than those in the lowest severity ranges to have an unmet need for specialty care. These findings are similar to those of a previous study that found an inverse relationship between health status and the likelihood of having ≥ 1 unmet need for care.¹ Those children with the highest severity ranks were equally as likely as those in the least-severe ranks to have an unmet

need for this care. It may be that there is a threshold at which a child's needs are so severe that their parent either becomes adept at navigating the health care system or receives assistance with care coordination or case management services.

The role of insurance in access to care has been demonstrated among the general pediatric population and CSHCN in multiple studies.^{1-3,15} Children without insurance have been shown to have consistently higher rates of unmet needs for health care than those with either private or publicly insured children. Similarly, we found that children who had been uninsured at any time during the 12 months before the survey faced great odds of having an unmet need for care. At a time when the futures of the Medicaid and SCHIP programs are uncertain due to budget shortfalls in nearly all states, access to care for poor and/or publicly insured CSHCN seems especially precarious. Our results highlight the importance of insurance coverage in minimizing barriers to receipt of needed care. Our findings of strong independent relationships between poverty status and having an unmet need for routine and specialty care are especially concerning.

We also found other predisposing characteristics that were associated with having an unmet need for routine or specialty care. In contrast to previous studies,¹ we found that African American children and those of multiple racial backgrounds were significantly more likely to report having an unmet need for routine care. In addition, children whose mothers had a high-school education or more than a high-school education were significantly less likely to report having an unmet need. Although age did not relate to the likelihood of having an unmet need for routine care, older children were significantly more likely to have an unmet need for specialty care.

The results regarding the relationship between provider supply and unmet need are intriguing. The findings that a higher general pediatrician/population ratio was significantly associated with a decreased likelihood of having an unmet need for routine care and that the supply of pediatric specialists was associated with a significantly higher likelihood of receiving needed specialty care are intuitive. As expected, neither the supply of generalist pediatricians nor the supply of internal medicine specialists was independently associated with receipt of needed specialty care. It should be noted, however, that the use of a substate-level variable in an individual-level analysis certainly carries the risk of ecological fallacy.

The National Survey of Children With Special Health Care Needs offers the health services research, policy, and health care communities an unprecedented opportunity to study the needs of chronically ill children in depth. It offers a large, recent, nationally representative sample of CSHCN and includes questions about their access to a variety of medical services. However, it has limitations that merit discussion.

One limitation of this study is its reliance on parental report of perceived need and receipt of services conditional on having a perceived need. The extent to which self-report of unmet need accurately

reflects evaluated need is unclear. Newacheck et al¹ have described the potential problems with self-report of unmet needs and alternative approaches in detail. We share the concern that prevalence estimates for unmet need based on parental report may underestimate or overestimate the true prevalence of need.

Consider the low levels of unmet need reported by Medicaid-insured children in our study: <10% of Medicaid-insured children in this survey reported not receiving needed specialty care. In contrast, Kuhlthau et al¹³ found very low rates of subspecialty care utilization in the 4 states for which they analyzed claims data. There are several possible reasons for the differences in these studies. First is that self-report of unmet need may be a poor proxy for true medical or "evaluated" need. When children with serious and complex medical conditions such as human immunodeficiency virus/acquired immunodeficiency syndrome and hemophilia do not have claims for subspecialty care, it raises concerns among medical professionals that they may not be receiving appropriate care. An uninformed parent, however, may not realize that subspecialty care may be beneficial for their child and not consider it to be "needed." In addition, the sample population for this study identified children whose need for medical services, prescription medications, or other services was greater than that of their peers and was expected to last for 12 months. This definition may have included children with mild chronic illnesses that do not require the care of a subspecialist. It is also important to note that the data from the Kuhlthau et al study preceded the National Survey of Children With Special Health Care Needs by 8 years and, as such, other changes over the time period may partly explain the differences in the findings.

Another limitation of our study is our inability to link these data with data on the local health care system. In addition, the limited data on the characteristics of children's insurance plans prevent us from exploring the extent to which having an unmet need for care may differ between children in managed care and those in other insurance arrangements. This is an important issue, because previous studies have found selective enrollment in health maintenance organizations by families with chronically ill children,¹⁶ decreased propensity to switch to a gatekeeping plan among families with chronically ill children,¹⁷ fewer subspecialist visits among chronically ill children who switched to gatekeeping plans versus those that remained in indemnity plans,¹⁷ and increases in the number of visits to subspecialists by chronically ill children after discontinuation of a gatekeeping arrangement.¹⁸

CONCLUSIONS

Our findings clearly demonstrate that a substantial minority of CSHCN have unmet needs for routine and specialty care. More importantly, our regression results highlight that important modifiable factors such as insurance and poverty status are associated with increased risk for having unmet needs for medical services. Future efforts to insure an equitable distribution of care receipt demand a better understanding of the reasons for these persistent relationships.

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