ARTICLE

Associations Between Quality of Primary Care and Health Care Use Among Children With Special Health Care Needs

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Objective: To determine whether parent-reported quality of primary care was associated with subsequent health care use for children with special health care needs.

Design: Secondary analysis of prospectively collected data.

Setting: The 2004-2005 and 2005-2006 Medical Expenditure Panel Survey panels.

Participants: A total of 1591 children with special health care needs.

Main Exposures: Composite measures for family centeredness of care, timeliness of care, and realized access derived from the Consumer Assessment of Healthcare Providers and Systems survey.

Main Outcome Measures: Rates of parent-reported emergency department visits (nonurgent and urgent) and hospitalizations. Only encounters occurring after completion of the Consumer Assessment of Healthcare Providers and Systems survey were assessed. Weighted multivariate Poisson regression analyses, yielding incident rate ratios, were used for analysis.

Results: Of the parents of the 1591 children included, 68.3% rated family centeredness, 51.5% rated timeliness, and 80.4% rated realized access as high quality. Low-quality family centeredness was associated with higher rates (incident rate ratio, 2.24; 95% confidence interval, 1.32-3.80) of nonurgent emergency department visits compared with corresponding rates associated with high-quality family centeredness. There were no associations between quality-of-care domains and rates of urgent emergency department visits. For privately insured children, low-quality family centeredness was associated with higher rates (incident rate ratio, 3.87; 95% confidence interval, 1.23-12.13) of hospitalizations compared with corresponding rates associated with high-quality family-centered care. For publicly insured children, no significant associations were found.

Conclusions: Parent-reported, low-quality family centeredness was associated with higher rates of subsequent nonurgent emergency department visits and hospitalizations among children with special health care needs. These findings highlight family-centered care as a critical area for primary care intervention to reduce potentially preventable health care use.

Arch Pediatr Adolesc Med. 2011;165(5):399-404

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Children with special health care needs (CSHCN) represent a high-cost and resource-intensive subgroup of children.[1-5] They are defined as those who have or who are at risk for having a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.[6] The prevalence of CSHCN has quadrupled in the past 4 decades, now comprising 12% to 16% of the pediatric population.[7-9] The increase in CSHCN is largely due to shifts in definitions from children with "disability/functional limits" to children with ongoing conditions needing or using a type or amount of services beyond that required of children generally. Medical care for CSHCN has a substantial effect on the health care system, whether measured in terms of health care use or medical expenditures. Children with special health care needs have 4 times the number of hospitalizations and twice the number of physician visits compared with those of the general pediatric population.[4] In 2000, this vulnerable subgroup of children accounted for approximately 42% of total medical expenditures for US children.[10]

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Improving the quality of primary care has been increasingly advocated as a strategy to reduce preventable health care use, especially among CSHCN.[11-16] In this population, use of high-acuity services, including the emergency department (ED) and inpatient wards, may represent inadequate primary care. Receipt of care in such environments can be problematic for CSHCN. Children with special health care needs may be cared for by staff

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unfamiliar with their extensive histories and diverse needs, and exposures to pathogens from other sick children may precipitate serious illness.[17] High-quality primary care has the potential to limit such interactions with the health care system. Although multiple studies have documented health care use and medical expenditures associated with CSHCN, many have been limited by cross-sectional data, and relatively few have assessed the impact of high-quality primary care on patterns of health care use.[1,2,4,18,19]

The Institute of Medicine's landmark document, *Crossing the Quality Chasm,* identified 6 quality-of-care domains (safety, effectiveness, patient or family centeredness, timeliness, efficiency, and equity) fundamental to improvement in care.[20] Increasing efforts have been directed toward assessment of quality-of-care domains through survey instruments. One such survey, the Consumer Assessment of Healthcare Providers and Systems (CAHPS), provides a valid measure of parent-reported quality of care for children, including CSHCN.[21] The CAHPS survey addresses family centeredness, timeliness, and aspects of effectiveness of care within primary care. Beginning in 2000, the Agency for Healthcare Research and Quality has included selected CAHPS questions in the Medical Expenditure Panel Survey (MEPS), thus providing a population-based point of reference for quality care.

The objective of this study was to determine the association between parent-reported quality of primary care in specific domains and subsequent health care use. We hypothesized that low-quality primary care, in the domains of family centeredness, timeliness, and realized access, would be associated with higher rates of subsequent pediatric ED visits and hospitalizations.

METHODS

STUDY DESIGN AND SOURCE OF DATA

This was a secondary analysis of prospectively collected data for the cohort of CSHCN (≤17 years of age) in the 2004 to 2005 (panel 9) and the 2005 to 2006 (panel 10) MEPS. This is a nationally representative survey of the US civilian noninstitutionalized population conducted annually by the Agency for Healthcare Research and Quality.[22] The MEPS consists of 3 interrelated surveys: the Household Component, the Medical Provider Component, and the Insurance Component. It collects data on health care use, expenditures, and insurance coverage. The MEPS uses an overlapping panel design in which data are collected through a preliminary contact followed by 5 computer-assisted, in-person interviews (rounds) during a 2-year period to collect household data, including demographic characteristics, perceived health status, insurance status, and health care use. The CAHPS questions are asked in the second round of interviews, allowing analysis of parent-reported quality of care and subsequent health care use within the database. For this study, we combined the Longitudinal Weight Files and ED Visit Files from the Household Component of panels 9 and 10.

STUDY POPULATION

All children who were screened as having a special health care need were eligible. The screening instrument used in MEPS is the CSHCN Screener. Although the full CSHCN definition includes an "at-risk" group, MEPS uses an identification method that does not feature this component of the definition. It identifies children who have a medical, behavioral, or other health condition that has lasted or is expected to last 1 year or longer, and it reports 1 or more of the following consequences of the condition: (1) using or needing more medical care, mental health services, or education services than other children of the same age; (2) using or needing prescription medication; (3) having limitations in their ability to do the things that most children of the same age do; (4) using or needing special therapies, such as physical, occupational, or speech therapy; or (5) using or needing emotional, developmental, or behavioral treatment or counseling.[23]

In accordance with a previous study,[24] we used a pattern of qualifying responses to the health consequences screening criteria to identify 4 mutually exclusive groups of CSHCN that represent varying levels of health status and complexity of health care needs: (1) CSHCN identified by current need for or use of prescription medication to manage an ongoing medical, behavioral, or other chronic health condition criteria and who qualified on no other CSHCN Screener criterion ("Rx meds only"); (2) CSHCN who qualified on 1 or more of 3 screening criteria for elevated service needs or use but who did not qualify on prescription medications or functional limitation ("elevated services only"); (3) CSHCN qualifying on the prescription medication screening criterion *and* 1 or more of the 3 criteria for elevated service use but not on functional limitation ("Rx meds/elevated services"); and (4) CSHCN qualifying on the functional limitation criterion, alone or in combination with any other screening criteria ("functional limitations").

OUTCOME MEASURES

The primary outcome measures were rates of parent-reported ED visits and hospitalizations. The urgency of the ED visit was determined by parent-reported resources used during the visit. This method of assigning urgency was used previously in large database studies.[25-27] Consistent with prior studies,[25] any visit that resulted in laboratory work, a radiograph, an electrocardiogram, an electroencephalogram, or admission to the hospital was defined as urgent; all other encounters were classified as nonurgent. The data for all encounters were recorded, and only those occurring after the completion date of the CAHPS survey (ie, subsequent to the assessment of quality of primary care) were included in the analysis. This corresponded to a 12-month follow-up period.

HEALTH CARE QUALITY DOMAIN WITHIN CAHPS

The quality of primary care received by the child was measured by the CAHPS questions within the MEPS. The 9 quality-of-care questions were grouped into composite scores for the 3 quality domains of family centeredness of care, timeliness of care, and realized access to care. The composite scores and question groupings were developed by the Agency for Healthcare Research and Quality. We scored the composites according to a previously published algorithm.[27,28] The composite scores for each child were obtained by averaging the individually answered questions that comprise the quality-of-care composites, with higher scores corresponding to higher quality. The individual questions constituting each composite and their Likert scales are listed in **Table 1**. As in previous studies, we dichotomized composite scores (high quality vs low quality), given the limited range of possible values.[27,28] Within the family-centeredness quality domain, the family is recognized as the principal caregiver and plays a central role in decision making. The *family centeredness* composite, scored on a 4-point Likert scale, was dichotomized, with a score higher than 3.5 indicating the highest-quality care and a score of 3.5 or less indicating lower-quality care. *Timeliness* refers to systematic reduc-

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tions in wait times and potentially harmful delays. Similar to family centeredness, the timeliness composite was scored such that a score higher than 3.5 indicated the highest-quality care and a score of 3.5 or less indicated lower-quality care. *Realized access* refers to a component of effectiveness that addresses whether families perceive problems in obtaining necessary care or referrals.[29] Questions were scored on a 3-point Likert scale. Scores were dichotomized as 3 vs less than 3.

PATIENT/FAMILY CHARACTERISTICS

Variables extracted from the MEPS data set included age (0-3 years, 4-12 years, or 13-17 years), sex, race/ethnicity, primary language (English vs other), and parent-reported child health status. Socioeconomic indicators included family income expressed as a percentage of the federal poverty level, health insurance, and the highest level of parental education.

This study was reviewed by the Baylor College of Medicine institutional review board, which determined it to be exempt from the need for its approval.

STATISTICAL ANALYSIS

Two separate longitudinal panels (2004-2005 and 2005-2006) of CSHCN were combined for the study. Analyses were weighted to account for oversampling within the MEPS design methodology and to yield national estimates for civilian noninstitutionalized children in the United States. Weights were provided by the Agency for Healthcare Research and Quality. Standard errors and test statistics were derived using STATA, version 10 for Unix (StataCorp LP, College Station, Texas), which takes into account the complex sample design of the survey.

Generalized Poisson regression analyses were used to assess associations between each quality-of-care composite individually and the number of subsequent encounters for ED visits and hospitalizations. Poisson regression was used because all outcome variables were counts. Results are reported as incidence rate ratios (IRRs) for the number of encounters per child. An IRR less than 1 indicates that lower quality care is associated with more encounters per child if $P < .05$. Each quality-of-care domain was analyzed in bivariate and multivariate, generalized, Poisson regression analyses with each measure of use. Determination of the Cronbach α was used to measure the intercorrelations among the questions composing each of the quality-of-care composites. If the Cronbach α values among the individual questions of a composite were low (<0.6), then the individual questions were used in analysis rather than the composite measure. All patient/family and socioeconomic covariates were entered into multivariate models. Variables were dichotomized if effects were similar across strata. Stratified analyses were completed because of interactions between insurance type and quality-of-care composites.

RESULTS

DEMOGRAPHIC CHARACTERISTICS

The demographic characteristics of the children are shown in **Table 2**. There were 1591 children eligible for the study. According to CSHCN subgroups, those in the Rx meds–only category composed the largest subgroup (41.3%) in the sample. Children ages 4 to 17 accounted for 85.3% of the CSHCN population. Two-thirds of CSHCN were non-Hispanic white, and English was the primary language in the homes of 94.2% of the children. More than 97% of children were insured, either publicly or privately. Two-thirds of the children were rated as having excellent or very good health status.

Table 1. Individual Questions Constituting the Quality-of-Care Composites in the Consumer Assessment of Healthcare Providers and Systems[a]

Quality-of-Care Composite
Family centeredness
How often provider explained things so you understood
How often provider showed respect for what you had to say
How often provider spent enough time with you
How often provider listened carefully to you
Timeliness
How often you got an appointment for injury or illness as soon as you wanted
How often you got a routine appointment as soon as you wanted
How often you were able to get help by telephone
Realized access
How big a problem it was to get care you or a doctor thought was necessary
How big a problem it was to get a referral to a specialist

[a] Highest quality was indicated by a composite score greater than 3.5 on the 4-point scale for family centeredness and timeliness (where 1 indicated never; 2, sometimes; 3, often; and 4, always) and a score of 3 on the 3-point scale for realized access (where 1 indicated a big problem; 2, somewhat of a problem; and 3, not a problem).

QUALITY-OF-CARE COMPOSITES

Analysis of parent-reported quality-of-care domains showed that 68.3% of parents rated the family centeredness of their child's primary care as high quality, 51.5% reported timeliness as high quality, and 80.4% reported realized access as high quality. Less than 30% of parents reported that their children received high-quality care in all 3 quality-of-care domains. Determination of Cronbach α values was conducted for all composites. For both family-centered care and realized access, the Cronbach α values among individual questions were all higher than 0.6. For timeliness of care, the Cronbach α values among individual questions were all less than 0.3. Therefore, the individual questions for timeliness were used in subsequent analyses rather than the composite.

ED USE

Analysis of ED use showed that 285 children (17.9%) had a total of 392 ED encounters. The number of ED visits ranged from 1 visit for 214 children to 8 visits for 1 child. The percentages of nonurgent and urgent visits were 48.0% and 52.0%, respectively. In multivariate analysis of nonurgent ED use (**Table 3**), low-quality family centeredness was associated with a higher rate of subsequent encounters compared with the corresponding rate for high-quality family centeredness (IRR, 2.24; 95% confidence interval [CI], 1.32-3.80). Of the individual questions for timeliness, only 1 question was associated with nonurgent ED visits. Children who were not able to consistently get an appointment for an injury or illness as soon as they wanted (ie, never/sometimes/often able) had higher rates of nonurgent ED visits (IRR, 1.59; 95% CI,

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Table 2. Characteristics of the Study Population for CSHCN

Characteristic	Percentage of Population[a]
Age, y	
0-3	14.7
4-12	57.9
13-17	27.4
Sex	
Male	57.4
Female	42.6
Race/ethnicity	
White	65.9
Hispanic	12.7
Black	16.0
Asian	1.5
Other	3.8
Insurance	
Private	63.6
Public	33.5
None	2.8
Income	
High	29.2
Middle	31.3
Low	14.4
Near poor	4.7
Poor	20.4
CSHCN subgroup	
Rx meds only	41.3
Elevated services only	17.6
Rx meds/elevated services	20.4
Functional limitation	20.7
Parental educational level	
High school or less	61.3
More than high school	38.7
Health status	
Excellent/very good	65.4
Good/fair/poor	34.6
Language spoken at home	
English	94.2
Spanish	4.5
Other	1.3
Quality-of-care composite	
Family centeredness	
≤3.5	31.7
>3.5	68.3
Timeliness	
≤3.5	48.5
>3.5	51.5
Realized access	
<3.0	19.6
3.0	80.4

Abbreviations: CSHCN, children with special health care needs; Rx meds, prescription medications.
[a] Percentages were derived from weighting to yield national estimates from the sample of 1591 children.

Table 3. Association Between Parent-Reported Low Quality of Care and Urgent and Nonurgent ED Visits[a]

Quality-of-Care Composite	ED Visits, IRR (95% CI)	
	Urgent	Nonurgent
Family centeredness	0.72 (0.43-1.19)	2.24 (1.32-3.80)
Timeliness	1.35 (0.87-2.10)	1.59 (1.07-2.36)[b]
Realized access	1.39 (0.81-2.37)	0.78 (0.46-1.33)

Abbreviations: CI, confidence interval; ED, emergency department; IRR, incident rate ratio.
[a] A multivariate, generalized Poisson regression analysis adjusted for age, sex, race/ethnicity, income, type of children with special health care needs, reported health status, parental educational level, and language in which the interview was performed.
[b] Significant relationship refers to how often the patient got an appointment for injury or illness as soon as he or she wanted.

Table 4. Associations Between Parent-Reported Low Quality of Care and Hospitalizations, Stratified by Insurance Type[a]

Insurance Type, Quality-of-Care Composite	IRR (95% CI)
Private	
Family centeredness	3.87 (1.23-12.13)
Timeliness[b]	. . .
Realized access	3.45 (1.30-9.19)
Public	
Family centeredness	1.37 (0.62-3.03)
Timeliness[b]	. . .
Realized access	0.40 (0.12-1.33)

Abbreviations: CI, confidence interval; IRR, incident rate ratio.
[a] A generalized Poisson regression analysis adjusted for age, sex, race/ethnicity, income, type of children with special health care needs, parental educational level, health status, and language spoken at home was performed.
[b] No significant relationships were found between individual timeliness questions and hospitalizations.

1.07-2.36) compared with the corresponding rates for those who were (ie, always able). There were no associations between quality-of-care domains and subsequent urgent ED visits.

In addition to quality-of-care composites, the CSHCN subgroup was also associated with ED use. Compared with the Rx meds–only group, those with Rx meds/elevated services use had a higher rate of nonurgent ED visits (IRR, 2.67; 95% CI, 1.52-4.68). Those in the functional limitations category had a higher rate of nonurgent visits (IRR, 2.08; 95% CI, 1.11-3.88) compared with the Rx meds–only group. No associations were found between CSHCN subgroup and urgent ED visits.

Of the sociodemographic variables, only young age (0-3 years) was associated with a higher rate of nonurgent ED visits (IRR, 2.80; 95% CI, 1.42-5.53) and urgent ED visits (IRR, 2.34; 95% CI, 1.06-5.18). Health status rated as good/fair/poor was associated with an increased rate of urgent ED encounters (IRR, 2.53; 95% CI, 1.51-4.23). None of the other child/family characteristics showed associations with ED use.

HOSPITALIZATIONS

Sixty-nine children (4.3%) were hospitalized for a total of 89 admissions. The number of hospital admissions ranged from 1 hospitalization for 59 children to 10 hospitalizations for 1 child. Because of significant interactions between quality-of-care domains and insurance type for the inpatient hospitalization outcome, the analysis was stratified according to insurance type (**Table 4**). Analysis of privately insured children showed that low-quality family centeredness was associated with more hospitalizations (IRR, 3.87; 95% CI, 1.23-12.13). Low-quality realized access was also associated with more hos-

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pitalizations (IRR, 3.45; 95% CI, 1.30-9.19). In contrast, none of the quality domains were associated with hospitalizations for publicly insured children. Of the sociodemographic variables, only young age (0-3 years) was associated with a higher rate of hospitalizations.

COMMENT

In this study, parent-reported low-quality primary care was associated with higher rates of nonurgent ED visits and hospitalizations for CSHCN. Low-quality family centeredness was associated with a higher rate of nonurgent ED visits. For children with private insurance, low-quality family centeredness and low-quality realized access were most strongly associated with higher rates of hospitalizations. Overall, these results provide new understanding on the relationships between the quality of primary care and high-acuity health care use among a vulnerable group of children.

As demonstrated in this study, family-centered care and realized access are critical components of primary care for CSHCN as they relate to nonurgent ED encounters and/or hospitalizations. If parents of CSHCN do not feel a partnership with their primary care physician, they may have more nonurgent ED visits and hospitalizations. Family-centered care has also been demonstrated to be an important element in parents' satisfaction with care, reported ease of using health care services, and health disparities among CSHCN.[30,31] In the case of realized access, if CSHCN do not have access to their primary care physician or referrals to subspecialty care, they may be more vulnerable to exacerbations of their chronic disease, which leads to hospitalizations.

In our study, low-quality family-centered care was associated with an increased rate of nonurgent ED visits, whereas it showed no associations with urgent ED visits. In 2 prior studies of the general pediatric population,[27,28] high-quality family centeredness was associated with fewer nonurgent ED visits. However, there were no associations between quality-of-care domains and urgent ED visits. These findings support our results. Children with special health care needs have greater levels of illness and may be anticipated to have more urgent ED visits. Although some visits may be preventable, others are not, especially those occurring at off hours. These urgent visits may not be able to wait for the primary care office to open. Family-centered primary care may not be able to affect this subset of ED visits. However, family-centered primary care may be able to reduce the number of nonurgent ED visits secondary to ambulatory care–sensitive conditions.

Because there were poor intercorrelations among the questions composing the timeliness-of-care composite, we conducted our analyses with the individual questions rather than the composite. Children who were not able to consistently get an appointment for an injury or illness had higher rates of nonurgent ED visits. These findings indicate that if CSHCN receive timely care from their primary care providers for injuries or illnesses, they will be less likely to seek ED care for nonurgent conditions. Prior studies from the literature show inconsistent findings on the relationship between timeliness of primary care and subsequent nonurgent ED visits. In a study also using MEPS data,[28] no relationship was found between timeliness and nonurgent ED visits. In another study using state Medicaid data,[27] high-quality timeliness of primary care was associated with an 18% lower nonurgent ED visit rate.

Our findings raise critical issues regarding the study of CSHCN and the quality of primary care. One issue is whether an integrated health care delivery model of primary care improves health care quality and relevant health outcomes, such as use of medical services. National initiatives increasingly focus on the medical home for CSHCN.[32] The American Academy of Pediatrics currently defines a *medical home* as care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.[33] Components of the American Academy of Pediatrics medical home overlap with the Institute of Medicine quality-of-care domains and the CAHPS questions regarding quality of care for children.

A systematic review of the evidence for the medical home for CSHCN showed that family centeredness, effectiveness, and timeliness were all important to improving health outcomes.[13] Children with special health care needs in primary care practices with higher scores on a medical home index have lower rates of hospitalizations.[34] Those with a medical home have lower odds of ED use and experience a reduction in racial/ethnic disparities in ED use.[19] By using longitudinal data, with quality of care assessed prior to service use, the present study allows for more causal inferences about subsequent use. Studies of the general pediatric population have also shown that quality-of-care components affect subsequent health care use.[27,28] This emerging literature provides further evidence that an integrated health care delivery model that addresses quality-of-care domains has the potential to improve care for CSHCN.

Our study provides continuing evidence that differentiating the heterogeneous group of CSHCN by the complexity of the child's health care needs has important research and policy implications. A previous study demonstrated that CSHCN with differing medical needs had distinct patterns of health care use, expenditures, and family burden.[24] Specifically, CSHCN in the Rx meds/elevated services and functional limitations groups had the highest ED use. Using the same methodology to develop subgroups of CSHCN, we generated similar findings with these 2 groups having the highest rates of nonurgent ED visits. These results suggest that different subgroups of CSHCN may require different interventions to improve quality of care and to reduce unnecessary ED use.

Our study also had several limitations. First, we used an average score to determine our quality-of-care composites. Other studies have used "all-or-nothing" algorithms to score composites. However, our methodology is supported by previous research.[27,28] Second, parental report is potentially subject to recall bias. However, parent report tools, such as those in MEPS, undergo rigorous assessment to mitigate such bias. Third, the classification of urgency of ED visits was based on the resources used during the ED visit. Therefore, some visits might have been misclassified. This may be especially true for

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CSHCN if ED physicians inappropriately order more interventions on the basis of the underlying chronic condition rather than the actual urgency of the visit. Fourth, the results regarding hospitalizations are derived from a small number of occurrences. Poisson regression is appropriate for such analysis of rare events. However, these results should still be interpreted with caution.

In conclusion, low-quality family centeredness was associated with a higher rate of nonurgent ED visits. Low-quality family centeredness and low-quality realized access were associated with higher rates of hospitalizations among CSHCN, although not uniformly across payer types. These findings highlight areas for improvement and intervention in health care delivery for CSHCN. Further studies are needed to assess the relationship between timeliness of care and health care use, given conflicting results between the current study and the existing literature.

Accepted for Publication: June 16, 2010.
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Financial Disclosure: None reported.
Funding/Support: This study was supported in part by grant HFP 90-020 from the Michael E. DeBakey Veterans Affairs Medical Center, Houston, Texas.
Disclaimer: The views expressed in this article are those of the authors and do not necessarily represent the views of the Department of Veterans Affairs.

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