Primary Health Care Quality in a National Sample of Children and Youth with Mental Health Impairment

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ABSTRACT: ***Objective:*** **To examine the general pediatric health care quality experiences of children and youth with mental health impairment.** ***Methods:*** **We conducted a cross-sectional analysis of 2006 Medical Expenditures Panel Survey data for children and youth aged 5 to 17 years (n = 7263). Mental health impairment was defined using the recommended cut-point (score ≥16) on the parent version of the Columbia Impairment Scale. Health care quality was measured with the Consumer Assessment of Healthcare Providers and Systems including parent ratings in 3 domains: provider communication, getting needed care, and getting care quickly. Logistic regression was used to test associations between mental health impairment and dichotomized Consumer Assessment of Healthcare Providers and Systems measures (poor vs good quality) adjusted for demographic characteristics, health insurance, and socioeconomic status. Analysis was conducted with Stata, Version 10.1 SE, and all estimates accounted for the Medical Expenditures Panel Survey complex sampling design.** ***Results:*** **In multivariable analysis, health care experiences of children with mental health impairment (versus those without) were consistently rated less favorably by parents, with greater odds of inferior quality of care ratings in all domains: getting needed care (odds ratio [OR] = 2.35), getting care quickly (OR = 1.41), physician communication (OR = 1.72), and overall health care quality (OR = 1.63).** ***Conclusions:*** **Further research is needed to identify specific aspects of care that families find problematic in relation to the organization and delivery of care within each quality domain. Interventions are needed to improve service systems for children and youth with mental health impairment, especially to support access to needed care.**

(*J Dev Behav Pediatr 31:*694–704, 2010) **Index terms:** quality of care, mental health impairment, Medical Expenditures Panel Survey, children, adolescents.

Mental health disorders, as a group, are the most prevalent chronic conditions in childhood and adolescence with up to 18% (median 12%) of children and youth affected.[1-5] Without successful treatment, mental disorders have significant adverse consequences for youths' physical health, academic achievement, social relationships, and quality of life.[6-8] Early treatment is crucial, because the onset of lifetime mental disorders often occurs in childhood or adolescence.[9] Unfortunately, many children and youth who need mental health services do not receive them.[10-17]

Pediatric primary care providers (PCPs) are key providers of mental health services for children and youth and often serve as gatekeepers for access to specialty mental health services.[18,19] Yet many pediatric PCPs cite barriers to providing adequate mental health services including lack of training and confidence to treat mental disorders, low availability of pediatric mental health services in the community, and long wait times for patients to see mental health providers.[20-22]

Patient experiences of care are important indicators of health care access and quality and serve as useful measures of the evaluation of health care system performance.[23] Effective physician-patient communication can improve patient satisfaction, adherence to treatment, and health outcomes.[24,25] Little is known, however, about these factors in primary care for the population of children and youth with mental health disorders. In the 2008 National Healthcare Quality Report, patient experiences with care were measured for all children and youth but differences in quality reports were not assessed by child mental health status.[26]

Evaluation of primary care experiences by child mental health status could help to pin-point specific aspects of care that families of children with mental health impairment identify as problematic. Such evaluation is especially important in light of the importance of primary care in the provision of pediatric mental health services.[18,19] This study was designed to compare parent reports of general health care quality for children and youth with and without mental health impairment. As consumers of health care for their children, parents are the best or

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only source of information for measures of health care quality such as physician-patient communication, the extent to which care is consistent with family needs and preferences, and experiences of barriers to care. Reflecting need for mental health services and potential problems with access,[20–22] we expected parents of children with mental health impairment to report more dissatisfaction with care.

METHODS

Sample

We analyzed cross-sectional data collected for the 2006 Medical Expenditures Panel Survey (MEPS), a nationally representative survey of the civilian, noninstitutionalized U.S. population. MEPS data are publicly available and the study was deemed exempt from review by the University of Washington Institutional Review Board. The sample included children and youth aged 5 to 17 years who visited a doctor's office or clinic to get health care in the prior 12 months (n = 5043). Observations were excluded from the study if they were missing data needed to measure the primary independent variable mental health impairment (n = 20), for a total of 5023 observations eligible for inclusion.

Dependent Variables

Health care quality was measured with the child version of the Consumer Assessment of Healthcare Providers and Systems (CAHPS), the most widely used survey instruments asking consumers about experiences with and evaluations of ambulatory care received from health care professionals and health plans (hereafter C-CAHPS). C-CAHPS is a previously validated standardized survey instrument, and data collection methodology designed specifically to measure patient-centered care and quality in pediatric settings from the consumer perspective.[27] C-CAHPS items in MEPS are included in a Parent Administered Questionnaire completed by a parent, usually the mother, for children younger than 18 years.

The C-CAHPS items in MEPS were used to develop standard CAHPSs composite measures supported by empirical testing in other work.[28] C-CAHPS composite measures were developed in 3 domains: provider-patient interactions; getting needed care; and getting care quickly.[28] Each composite measure was constructed from 2 to 4 parent-report items each coded on a 4-point scale (Always, Usually, Sometimes, Never) or a 3-point scale (Not a problem, a small problem, a big problem). Individual items were recoded as missing if originally coded do not know or refused. The item-specific number of recodes ranged from 1 to 78.

Previous studies of healthcare quality ratings have documented the tendency of consumers to rate their health care experiences favorably.[29–31] Accordingly, consumer quality ratings are typically positively skewed, with a substantial proportion of respondents giving their care the highest possible rating, also known as "top box" rating. To address this tendency, we followed Elliott et al,[29] and coded the composites in 2 stages. First, to address the positively skewed distribution, we distinguished responses in the most positive category from the other responses to create binary indicators of the best quality care for each parent-report item. For each item, the "top box" responses were ratings of either "Always" or "Not a problem." Second, we developed binary indicators for each composite, coded as 1 if all parent report items for the composite had top box ratings and otherwise 0. Any single item coded as not applicable (e.g., problems seeing a specialist if the child did not require specialty care) was excluded from the composite for the individual.

The C-CAHPS module includes an overall rating of the child's health care from 0 to 10, where 0 is the worst care possible and 10 is the best care possible. This item was examined as a binary dependent variable with responses of 9 or 10 included as the top box scores because evidence supports this cut-point as the best approach to reduce sensitivity to patient positive response tendency.[29–31]

For ease of exposition of the findings, the 4 binary outcome measures—the 3 composites and the overall health care rating—were reverse recoded (1 = less than top box/poor quality, 0 = top box/good quality) for use in the statistical models. This approach yielded more readily interpretable odds ratios (ORs) that were greater than 1 if children with mental health impairment were more likely to report receiving less than best quality care than their counterparts without impairment.

Mental Health Impairment

Child/youth mental health impairment was defined as a binary variable using the recommended cut-point (score ≥16) on the parent version of the Columbia Impairment Scale (CIS), a 13-item instrument designed to be administered by parents and included in the MEPS Parent Administered Questionnaire. Parent respondents were asked to rate each CIS item on a 5-point scale (0 = "no problem" to 4 = "a big problem") for their children aged 5 to 17 years. The CIS reliably assesses impairment over 4 areas of functioning including interpersonal relations, psychopathological domains (e.g., depression, anxiety, behavior problems), functioning at school, and leisure time.[32] The CIS cut-point (≥16 points) was derived by Bird et al,[32] using discriminant function analysis to distinguish those children more likely versus less likely to have mental health impairment. Construct, discriminant, and concurrent validity of the binary CIS measure is well supported with strong associations to established indicators of mental dysfunction, measures of help-seeking, and clinician ratings of global impairment. A continuous measure of impairment was considered for the analysis but rejected as it would not clarify to what degree the estimates reflect differences between those with and without mental health impairment. Moreover, differences in health care quality ratings associated with a binary measure of impairment (yes/no) were viewed as more easily interpreted than those associated with a continuous measure and the interpretation may be more clinically relevant.

In descriptive analyses, children and youth in the sample were classified as having any mental health disorder (yes = 1, no = 0) if any International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code from 294 to 319 was recorded in MEPS. Medical conditions reported by MEPS respondents are recorded by the interviewer as verbatim text, and later coded by professional coders to ICD-9-CM codes and collapsed to 3-digit codes to preserve confidentiality. All codes were verified and error rates did not exceed 2.5% for any coder.[33]

Other Covariates

Variables expected to influence health care access and quality were selected based on the Anderson and Aday model of health care access and utilization.[34] Predisposing variables (i.e., demographic and other background characteristics) included child sex (female = reference, male), the child's age in years (5 to 8 years, 9 to 12 years, 13 to 17 years = reference), parent-reported racial/ethnic group (white non-Hispanic = reference, black non-Hispanic, Hispanic, and other non-Hispanic), census region of residence (South = reference, Northeast, Midwest, West), and an indicator of family size >4 (1 = yes, 0 = reference). Enabling factors (i.e., health insurance and other resources) included family income as percentage of the federal poverty line (<100%, 100 to <125%, 125 to <200%, 200 to 400%, >400% = reference), medical insurance status (measured hierarchically and categorized as any private insurance = reference, public insurance only, uninsured), caregiver education level (<12 years, 12 years only = reference, >12 years to <16 years, ≥16 years), an indicator of having married parents (1 = yes, 0 = reference) and the respondents' (usually mothers') mental health status coded on a 5-point scale as 1 = Excellent, 2 = Very Good, 3 = Good, 4 = Fair, or 5 = Poor. An indicator of possible caregiver depression, derived from an item in the Patient Health Questionnaire-2[35] asking whether the respondent felt downhearted or depressed in the past 4 weeks (1 = yes, 0 = reference) was also controlled. Need (i.e., perceived or evaluated health status) was measured as child mental health status coded as described above for mother's mental health status. To help to differentiate the influence of health impairment generally from that of mental health impairment on quality ratings, all models included an indicator of whether the child had special health care needs (1 = yes, 0 = reference), defined as having a chronic condition and a need for health services beyond what is required by children in general.[36] Finally, all models included a count of the number of office-based visits the child had in the prior year, which serves as a measure of need and also accounts for possible confounding of the measured associations by frequency of health system contact.

The child and maternal measures of mental health status were highly correlated with similarly coded measures of general health status (r = .70 and r = .61 for children/youth and parents, respectively). Therefore, only mental health status was included in the statistical models in separate measures for children/youth and their parents. For children and youth, this variable serves as a proxy measure of mental health symptom severity.

Statistical Analysis

Bivariate analysis was conducted for each of the study variables by child mental health impairment. Each binary C-CAHPS composite measure was modeled using logistic regression, controlling for child mental health impairment (1 = yes; 0 = reference) and the predisposing, enabling, and need covariates. Models were retested with interaction terms for mental health impairment with age, sex, race/ethnicity, insurance status, and socioeconomic status. Partial f tests were used to test the significance of the interaction terms and, if indicated, stratified models were estimated.

In exploratory subanalysis, the adjusted regression models were repeated in the subset of children and youth with the 2 most common diagnoses (hyperactivity and depression—representing externalizing and internalizing disorders, respectively), with an indicator of depression only (1 = yes; 0 = hyperactivity only or both depression and hyperactivity) included as the primary independent variable.

All analysis was conducted using Stata statistical software (College Station, TX) Version 10.1 SE. Stata survey commands and person-level weights were used to correct standard errors for the MEPS complex sampling design and to make the estimates representative of the civilian, noninstitutionalized U.S. population. Given 4 distinct outcomes, the Bonferroni correction was used to set the level of significance for the study at p = .0125 (i.e., 0.05/4) and address the issue of multiple comparisons.

RESULTS

Characteristics of the Study Sample

Most of the children and youth were white, non-Hispanic (58%), aged 13 to 17 (40%) with private health insurance (65%) and family income at or above 200% of the federal poverty level (62%). Compared to children without mental health impairment, a greater proportion of those with impairment were white, non-Hispanic, aged 9 to 12 and had public health insurance, special health care needs, lower family income, and more office-based visits (Table 1). Both parents and youth in the mental health impairment group had less optimal mental health status.

The sample prevalence of mental health impairment using the CIS was 14% and the prevalence of having any recorded International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis in

Table 1. Characteristics of Children and Youth in MEPS 2006 by Mental Health Impairment

		Mental Health Impairment[a]		
	Total	**CIS < 16**	**CIS ≥ 16**	***p***
Total	5,023	4,279	744	
Age (years), %				<.01
5–8	30	31	18	
9–12	30	30	32	
13–17	40	39	50	
Gender, %				
Male	51	51	54	.23
Race/ethnicity, %				
White non-Hispanic	58	57	64	<.01
Black non-Hispanic	15	15	16	
Hispanic	19	20	12	
Other non-Hispanic	8	8	8	
Insurance, %				<.01
Private insurance	65	66	58	
Public insurance	28	27	37	
No insurance	7	7	5	
Child mental health status, %				<.01
Excellent	52	57	18	
Very good	27	27	23	
Good	17	14	26	
Fair	3	1	18	
Poor	1	1	5	
Caregiver mental health status, %				<.01
Excellent	34	36	16	
Very good	33	33	27	
Good	27	26	41	
Fair	5	4	12	
Poor	1	1	4	
Caregiver down or depressed, %	24	21	40	<.01
Child with special health care needs, %	24	19	59	<.01
Total number out-patient visits	2.88	2.27	6.99	<.01
Mean	2.62	2.12	5.44	
SD	3.13	2.42	8.54	
Family size >4, %	41	41	36	.06
Family income level (%FPL)				<.01
<100	16	15	22	
100–<125	5	5	4	
125–<200	16	16	18	
200–<400	34	34	34	
≥400	28	30	22	
Caregiver education, %				.01
Less than high school	17	17	17	
High school	30	28	34	
Some college	26	26	27	
College graduate	27	28	21	
Parent marital status, %				<.01
Married	72	74	58	
Region of residence, %				.01
Northeast	18	18	12	
Midwest	22	22	26	
South	36	36	36	
West	24	24	26	

MEPS, Medical Expenditures Panel Survey; CIS, Columbia Impairment Scale.

[a] Mental Health Impairment defined as score ≥16 on the Columbia Impairment Scale.

Medical Expenditures Panel Survey (MEPS) was 9%. The most prevalent mental health conditions were hyperactivity and depression, recorded for 5% and 2% of the sample, respectively. Of those children classified as having no mental health impairment using the CIS, 91% had no recorded mental health diagnosis in MEPS; of those classified as having mental health impairment, 54% of the children had no recorded mental health diagnosis in MEPS.

Top Box Ratings by Mental Health Impairment

The proportion of the study sample reporting top box ratings for the C-Consumer Assessment of Healthcare Providers and Systems (CAHPS) composites and the individual survey items are summarized in Table 2. The analysis sample sizes varied for each composite measure according to applicability of the underlying items for the respondents. The measures were compared by mental health impairment, by having any mental health diagnosis and by specific diagnosis in the subset of children and youth with depression only versus hyperactivity only.

Compared to children without mental health impairment, fewer children with mental health impairment under any definition (i.e., CIS scores ≤16, reported diagnosis) had top box ratings for all individual C-CAHPS items, for the 3 C-CAHPS composites (getting care quickly, getting needed care and physician communication) and for overall health care quality (Table 2).

There were fewer differences in the proportion with top box ratings for children and youth with hyperactivity versus depression diagnoses. On all measures, parents of children with hyperactivity reported consistently higher quality ratings than did those of children with depression, although their ratings were consistently lower than those with children classified as having no mental health impairment using the CIS.

Associations between Consumer Assessment of Healthcare Providers and Systems Composite Measures and Mental Health Impairment

The bivariate findings were robust in the face of controls for important predisposing, enabling, and need factors (Table 3). Children with mental health impairment were significantly more likely to have a parent report of having less than best quality care in the domain of getting needed care (odds ratio [OR] = 2.35; 95% confidence interval [CI] = 1.67–3.30). Other factors associated with lower quality ratings in this domain were having public insurance compared to private insurance and poorer mental health status. Children with mental health impairment were also more likely to have a parent report of lower quality care in the domains of getting care quickly (OR = 1.41; 95% CI = 1.06–1.86). Finally, children with mental health impairment were more likely to have a parent report of less than best quality care related to provider communication (OR = 1.72; 95% CI = 1.32–2.24). Children with special health care needs and those whose caregiver reported feeling down or depressed also had lower quality ratings for getting care quickly (OR = 1.23; 95% CI = 1.02–1.48 and OR = 1.21; 95% CI = 1.01–1.46, respectively).

Overall ratings of health care quality were more likely to be below 9 on the 10-point scale among children with mental health impairment compared to those without (OR = 1.63; 95% CI = 1.21–2.19). Poorer child mental health status, special health care needs and caregiver report of feeling down or depressed were also associated with lower overall ratings of health care quality, whereas female children were less likely to have reports of poor quality care.

In the subanalysis comparing children and youth with a diagnosis of depression to those with a diagnosis of hyperactivity, there were no significant differences in the odds of parent-reported problems with physician communication, getting needed care or getting care quickly. Children and youth with a depression diagnosis had greater odds than those with hyperactivity of their parents reporting less than best quality care in their overall ratings of health care quality (OR = 2.46; 95% CI = 1.18–5.11).

We found no effect modification of the associations between mental health impairment and health care quality reported in Tables 3 and 4 by the child's age, sex, or socioeconomic status. There were significant differences by race/ethnicity in the domain of physician communication with greater odds of less than best quality care reported by parents of children and youth who were white, non-Hispanic (OR = 1.86; 95% CI = 1.29–2.66) and black, non-Hispanic (OR = 2.15; 95% CI = 1.31–3.54). These associations were not significant among children and youth who were Hispanic or other, non-Hispanic. There was also significant effect modification of the association between mental health impairment and overall quality ratings by health insurance status with uninsured children and youth (OR = 8.60; 95% CI = 1.83–40.333) and those with some public insurance (2.58; 95% CI = 1.70–3.90) having greater odds of poor quality ratings. This association was not significant for children with private health insurance.

DISCUSSION

In a national sample of children and youth, mental health impairment was consistently associated with lower quality of health care from the consumer perspective. Children and youth with mental health impairment experienced problems getting needed care, getting care quickly and with provider communication; furthermore, their parents were more likely to provide less favorable overall health care quality ratings. These findings persisted in models controlling for important predisposing, enabling, and need factors including socioeconomic status, health insurance, maternal and child health status, and visit frequency.

Table 2. Healthcare Quality for Children and Youth in MEPS 2006 by Mental Health Impairment

		Percentage with Top Box Rating[b]								
		MH Impairment			MH Diagnosis			Specific Diagnosis		
C-CAHPS Composite	**Survey Item[a]**	**CIS <16**	**CIS ≥16**	***p***	**None**	**Any**	***p***	**ADHD**	**Depression**	***p***
Getting care quickly	n = 4,629	70	55	***	68	62	**	65	48	***
	When care needed right away for an illness, injury, or condition, how often did child get care as soon as wanted?	93	86	***	92	89	*	92	84	
	Not counting times child needed care right away, how often did child get an appointment for health care as soon as wanted?	72	58	***	71	64	**	66	50	***
Getting needed care	n = 2,806	89	63	***	87	72	***	75	62	**
	How much of a problem, if any, was it to get the care, tests, or treatments you or a doctor believed necessary?	94	77	***	92	84	***	84	81	
	How much of a problem, if any, was it to see a specialist the child needed to see?	92	71	***	91	77	***	82	68	**
Provider Communication	n = 4,993	65	46	***	63	55	***	53	49	
	How often did child's doctors or other health providers listen carefully to you?	78	62	***	76	69	***	69	62	
	How often did child's doctors or other health providers explain things in a way you could understand?	79	69	***	78	75		73	76	
	How often did child's doctors or other health providers show respect for what you had to say?	80	64	***	79	72	**	73	65	
	How often did child's doctors or other health providers spend enough time with child?	73	58	***	71	67		68	60	
Overall Quality Rating	n = 5,023									
	Using any number from 0 to 10 where 0 is the worst health care possible, and 10 is the best . . . , what number would you use to rate all of the child's care?	70	47	***	68	57	***	58	43	**

MEPS, Medical Expenditures Panel Survey; CAHPS, Consumer Assessment of Healthcare Providers and Systems; CIS, Columbia Impairment Scale; MH, mental health; ADHD, attention-deficit hyperactivity disorder.

[a] All survey items apply to the 12 months preceding the interview.

[b] Top box rating is defined as rating all items in the composite "Always" or "Not a problem" (i.e., the highest possible quality) or scoring the overall quality measure as 9 or 10.

***$p < .01$; **$p < .05$ and $p > .01$; *$p < .10$ and $p > .05$.

Table 3. Logistic Regression C-CAHPS Composite Ratings of Less Than Best Quality Care on Mental Health Impairment[abc]

	Access-Getting Needed Care			Access-Getting Care Quickly			Provider Communication		
	OR	**95% CI**	***p***	**OR**	**95% CI**	***p***	**OR**	**95% CI**	***p***
Mental health impairment	2.35	1.67–3.30	<.01	1.41	1.06–1.86	.01	1.72	1.32–2.24	<.01
Age (years)									
5–8	1.30	0.90–1.88	.17	0.92	0.76–1.12	.41	1.01	0.84–1.21	.93
9–12	1.19	0.85–1.68	.31	0.88	0.72–1.07	.20	0.85	0.70–1.03	.09
12–17 (reference)	—	—	—	—	—	—	—	—	—
Sex									
Female	1.10	0.81–1.52	.51	1.03	0.87–1.20	.75	1.01	0.89–1.16	.83
Male (reference)	—	—	—	—	—	—	—	—	—
Race/ethnicity									
White, non-Hispanic (reference)	—	—	—	—	—	—	—	—	—
Black, non-Hispanic	0.80	0.53–1.21	.3	1.18	0.92–1.52	.19	0.90	0.68–1.19	.44
Hispanic	0.98	0.66–1.45	.92	1.15	0.88–1.51	.30	1.19	0.93–1.53	.17
Other	1.36	0.78–2.37	.27	0.83	0.56–1.21	.34	1.11	0.75–1.64	.60
Health insurance									
Private only (reference)	—	—	—	—	—	—	—	—	—
At least some public	1.61	1.07–2.44	.02	1.07	0.83–1.37	.61	1.08	0.85–1.38	.52
Uninsured	1.70	0.88–3.29	.12	1.36	0.89–2.05	.15	1.38	0.91–2.09	.12
Child mental health status	1.53	1.29–1.83	<.01	1.13	0.98–1.30	.07	1.12	1.01–1.25	.04
Special health care needs	1.13	0.87–1.22	.45	1.23	1.02–1.48	.03	1.21	1.01–1.46	.04
Caregiver down or depressed	1.39	0.94–2.06	.09	1.36	1.08–1.72	.01	1.24	0.98–1.58	.08

CAHPS, Consumer Assessment of Healthcare Providers and Systems; OR, odds ratio; CI, confidence interval.

[a] Mental Health Impairment defined as score > 16 on the Columbia Impairment Scale.

[b] Models controlled for residence in MSA, region of residence, maternal education, family size, family income as % of Federal Poverty Level.

[c] Each composite is coded 1 = less than best quality, 0 = best quality.

Our study adds important information about parent assessments of the primary health care experiences of children and youth with mental health impairment. To date, numerous studies have identified problems with access and unmet need for mental health services among U.S. children and youth.[10–12] Far fewer have examined parent satisfaction with health care experiences for children with special health care needs[23,37] or developmental disorders,[38,39] and none to date have focused on the primary care experiences of children with mental health impairment. Because primary care is often the gateway for accessing mental health services,[18] the quality of general pediatric care is of equal or possibly greater importance than the quality of mental health specialty care.

The differences we found in parent perceptions of primary health care quality by mental health impairment highlight the need for care provided within a medical home as promoted by the American Academy of Pediatrics, i.e., community-based primary health care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.[40] Nationally, improvements have been reported in general pediatric health care, with fewer parents reporting communication difficulties with their physicians in 2005 than in 2001 (5.5% compared to 7%).[26] Our findings suggest that these benefits may not be realized to the same extent by children and youth with mental health impairment. Yet, there is evidence that parents of children with some mental health disorders are less likely to report receiving care consistent with the medical home model than are children with asthma or those with other special health care needs.[39] Further, given the problems parents report getting access to needed care it would be critical that a medical home for children in this population have the capacity to respond to crises.

The health care quality estimates associated with mental health impairment were consistently of greater magnitude and significance than those associated with the child's status as having special health care needs (CSHCN). Since we controlled for CSHCN, the estimates for the odds of unfavorable quality ratings associated with mental health impairment can be interpreted as the effect over and above the child having need for health services beyond what is required by children generally. Interestingly, the CSHCN variable was independently associated with less favorable health care quality ratings. We found no prior studies of health care quality that

Table 4. Logistic Regression of Overall Quality Rating <9 on Mental Health Impairment[ab]

	Overall Quality Rating <9		
	OR	**95% CI**	***p***
Mental health impairment	1.63	1.21–2.19	<.01
Age (years)			
5–8	0.97	0.81–1.17	.78
9–12	0.97	0.80–1.17	.76
13–17	—	—	—
Sex			
Female	0.84	0.73–0.98	.02
Male (reference)	—	—	—
Race/ethnicity			
White, non-Hispanic (reference)	—	—	—
Black, non-Hispanic	0.95	0.70–1.29	.74
Hispanic	1.10	0.85–1.41	.48
Other	1.27	0.87–1.85	.21
Health insurance			
Private only (reference)	—	—	—
At least some public	1.14	0.88–1.47	.32
Uninsured	1.34	0.85–2.12	.21
Child mental health status	1.28	1.13–1.47	<.01
Special health care needs	1.27	1.05–1.54	.01
Caregiver down or depressed	1.46	1.16–1.83	<.01

OR, odds ratio; CI, confidence interval.

[a] Mental Health Impairment defined as score > 16 on the Columbia Impairment Scale.

[b] Model controlled for child age, sex, race/ethnicity, residence in metropolitan statistical area (MSA), family size, family income as a percent of the Federal Poverty Level, parent marital status.

differentiate between mental health and other special health care needs. Our finding that mental health impairment was independently associated with parental report of less than optimal primary care may reflect well-documented problems with access to care or difficulties associated with treating mental disorders cited by clinicians including inadequate training and concerns about preparedness to treat specific disorders.[20-22] The complexity of the healthcare needs of children with mental health impairment may exceed the capacity of the primary care system as it is most often organized.

In the subanalysis, quality ratings for physician communication and getting needed care were no different for children and youth with a diagnosis of depression compared to those with hyperactivity; however, depression (versus hyperactivity) was associated with lower quality of care in the domain of getting care quickly and with lower overall quality ratings. Attention-deficit hyperactivity disorder is one of the most common disorders—mental health or otherwise—encountered today in pediatric primary care settings. Moreover, studies indicate pediatricians report lower levels of concern about their preparedness to diagnose and manage attention-deficit hyperactivity disorder relative to other conditions.[20,41] Primary care provider (PCP) preparedness to manage common conditions may be an important aspect of parents' perceptions of the quality of care their children receive.

Black, non-Hispanic, and Hispanic parents of CSHCN are disproportionately more likely to report dissatisfaction with care compared to white, non-Hispanic parents.[23,42,43] In this study, conditional on the child having special health care needs, white non-Hispanic and black non-Hispanic parents of children with mental health impairment were more likely to provide lower quality ratings in the domain of physician communication whereas this association was not significant for Hispanic or other/non-Hispanic children and youth. These differences may reflect cultural or other differences in the ways in which parents endorse quality of care ratings by race/ethnic group or possibly the disproportionate disadvantage relative to controls apparent in the population with mental health impairment in our sample (Table 1). It is also possible that our control for special health care needs status accounts for some of the race/ethnic differences in quality ratings reported in other work. Results of the stratified analysis indicated those with public insurance or without insurance were far more likely to rate their children's care unfavorably (results not shown in tables). Because there were no comparable differences by insurance status in the other models, these results likely reflect differences in family experiences by insurance status in other domains, possibly care coordination, continuity of care, or access to family centered care.

Caregiver report of feeling down or depressed was associated with lower quality ratings for getting care quickly and overall satisfaction with care and was marginally significantly associated with the other 2 domains we examined. Alternative measures of caregiver mood, if available, may have been significant in all domains. Depressed mood may influence caregiver ratings of child health care quality through several mechanisms including perceptions of need, intensity of health service use, adherence to treatment, or reporting tendencies. Caregiver self-reported health status, which is likely to be highly correlated with self-report of mental health status, has been shown to be negatively associated with quality ratings of child health care[44] and could reflect differences in patient satisfaction reporting tendencies that are well supported in previous research.[45] Nevertheless, our findings of lower quality health care ratings from the caregiver perspective were robust over and above the influence of this important confounding factor.

Some of the quality estimates reported in Tables 3 and 4 were attenuated and some were no longer significant in models that included an indicator of having a mental health diagnosis rather than an indicator of mental health impairment (not shown in tables). Possibly, the greater magnitude and significance of estimates associated with mental health impairment reflect unmet mental healthcare needs of those children categorized as having impairment but no formal diagnosis. Parents of children with unmet needs are likely those experiencing structural or other barriers to receipt of mental health services as reported in prior studies (e.g., low availability of providers, long waits, stigma, lack of trust).[46,47] As a result, they may perceive their child's healthcare less favorably than parents whose children are receiving ongoing treatment for a known diagnosis. With treatment, children and youth with a mental health diagnosis may experience improvements in their conditions, which could influence their parents rating of their health care quality. Other unmeasured factors including parental understanding of the disorder, condition severity, the structure of the treatment setting, or specific elements of the treatment process may further explain differences in health care quality estimates between youth classified as having mental health impairment versus a medical diagnosis.

Our measure of provider communication is based on items comparable with those used to measure experiences of care for children in the 2008 National Healthcare Quality Report.[26] In the national report, 5% of parents reported poor communication with their physicians in 2005, defined as health providers sometimes or never listened carefully, explained things clearly, showed respect for what they had to say, or spent enough time with them. Our "top box" coding method included responses of always in the definition of poor communication, resulting in a much greater proportion of families reporting problems on individual survey items as well as on the composite measure (Table 2). Even still, recoding the individual survey items with the method used in the national report, children and youth with mental health impairment remain significantly more likely to experience poor quality care than their counterparts without impairment: 12% versus 5% for not spending enough time, 8% versus 3% for not showing respect, 7% versus 3% for not explaining things clearly, and 9% versus 3% for listened carefully. These findings are particularly concerning given the complexity of mental health services and the challenges already inherent in provider communication in pediatric settings where a third party, usually a parent or guardian, is involved in decision making and expressing the child's health care needs and preferences.[26]

Study strengths include a large national sample and a global measure of mental health impairment that permits inclusion of the experiences of children with impairment who have not formally received a diagnosis. Our estimates are clinically meaningful and statistically significant even with the Bonferroni correction applied to account for our examination of multiple outcomes.

Interpretation of the study findings is subject to limitations. Our focus on general pediatric health care does not separate quality ratings for mental health services from those of other health services delivered in primary care settings. The Columbia Impairment Scale (CIS) measure available in Medical Expenditures Panel Survey (MEPS) is validated only as a binary measure of impairment, which does not account for the child's level of functioning and leaves to future research the question of whether very high levels of impairment are associated with very high levels of consumer dissatisfaction in a dose–response relationship. The CIS relies on a lay person's report, not a clinical evaluation, so the presence or absence of impairment may be subject to misclassification.[32] If this misclassification is nondifferential our associations would be biased toward the null and our findings conservative. However, we cannot rule out the possibility that factors associated with misclassification of mental health impairment are also associated with health care quality thus leading to stronger or weaker associations than those we have reported. Our measure of children and youth having a mental health diagnosis was based on parent-report, and we cannot assume that respondents always report condition data that can be coded accurately.[48–50] Further research is needed to examine the health care experiences of children and youth classified as having mental health disorders by clinical diagnosis. We cannot rule out that our findings are influenced by unmeasured factors (e.g., family health beliefs, health behaviors, care site-specific factors, programmatic interventions, and expectations of care) that are associated with rated experiences of health care quality and with mental health impairment. There may also be differences between satisfaction expressed and the actual quality of the services provided that we are unable to quantify.[51] Independent of the care delivered, family experiences of health care quality may be influenced by changes in the child's condition, which we are unable to measure.

CONCLUSIONS

Children and youth with mental health impairment experience problems with provider communication, getting care quickly, and especially with getting needed care. Their parents also provide lower ratings of their overall health care quality. Further research is needed to disentangle the specific aspects of healthcare that families identify as problematic in each domain in relation to organization and delivery of care. Studies are also needed to design and test interventions designed to improve healthcare quality for this population. Interventions focused on improving access to needed care and the provision of healthcare consistent with the medical home model could prove fruitful. Improving the organization and delivery of care to support access to needed care and other quality outcomes for children and youth with mental health impairment is an essential step toward addressing unmet needs as well as supporting the translation of promising research findings into clinical practice.

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Book Review

Getting the Best for Your Child with Autism, An Experts Guide to Treatment

by Bryna Siegel, New York, NY, Guilford Publications, 2008, 280 pp, Paperback, $16.95.

Dr. Bryna Siegel has written another great book for parents of children with autism. The introduction sets the tone of the entire book, as its purpose is to arm parents with knowledge, so that they can then be the best advocates for their child with autism. She empowers parents by providing them with information about autism, diagnosis, and treatment.

The book is divided into 4 parts. In Part 1, she describes the process of developmental screening and evaluation. She explains, in good detail, the difference between evaluation for diagnosis and evaluation for intervention and treatment planning. This is the only section in which she demonstrates some bias toward psychologists when compared with child psychiatrists and developmental-behavioral pediatricians. Certainly, there are autism experts in each of these fields, with knowledge and ability varying by the individual practitioner.

Part 2 is about what to do after the parent has received the diagnosis. With great compassion, Dr. Siegel reminds parents that they need to take care of themselves to be able to take care of their newly diagnosed child. She also reminds them, gently, to take care of their other children as well. The family still needs to function. She then guides parents through the maze of the Internet and how to choose providers who will be the best fit for the individual child and the family.

Part 3 is about treatment. However, before diving into the different treatment models (which she addresses in great detail later in this part), Dr. Siegel identifies autism-specific learning styles and autism-specific learning disabilities. She explains that each and every individual child has different autism-specific learning weaknesses and autism-specific learning strengths. The autism-specific learning styles is the way that the individual child's relative strengths and possibly odd talents (such as a great memory) can be used to help the children learn things they need to learn. The autism-specific learning disabilities are areas that need to be addressed. This then lays the groundwork for the child's intervention, whether it is through an applied behavioral analysis (ABA)-type of program or the child's individualized educational plan through the school district. Later, in Part 3, she guides parents through generating a table of each area (social, language, play, repetition needs, and sensory needs) to develop the child's learning profile. Then, Dr. Siegel provides a detailed description of the different treatment models for autism. With the child's learning profile in hand, the parents can make a more informed decision about what treatment model would best help their individual child, developing their child's "customized course" of treatment.

Part 4 engages the assistance of special education attorney, Kathryn Dobel, to walk parents through their legal rights with respect to their child's treatments. Once again, being provided with this type of knowledge is empowering to parents. However, Dr. Siegel then reminds parents of their responsibilities to work collaboratively and respectfully with their child's providers and educators.

Parents and providers would all benefit from reading this comprehensive resource. For those parents who read and use this book to guide them through the process, their child will be the one who benefits the most.

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