


Disparities in Patient- and Family-Centered Care Among Children With Health Conditions

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Abstract

The objective of this study was to estimate and compare the prevalence of patient- and family-centered care (PFCC) received by children in the United States (US) with chronic and developmental health conditions and determine associations between the presence of the conditions and parents' perceptions of PFCC after controlling for covariates. Linked data from the 2012–2016 National Health Interview Survey (NHIS) and 2013–2017 Medical Expenditure Panel Survey (MEPS) ($n = 7,835$) were tested using crude and adjusted logistic regression procedures. Parents of children with developmental delays had 32% lower odds (95% CI = 0.51–0.90) of reporting their healthcare provider always exhibited all PFCC qualities. Parents of children with allergies and developmental delays had 26% (95% CI = 0.58–0.95) and 42% (95% CI = 0.42–0.80) lower odds of reporting their provider always listened carefully compared to parents whose children did not. Findings demonstrate the importance of continuous training for providers to tailor communication for families who have children with health conditions.

Keywords

patient-centered care, family-centered care, patient-provider communication, pediatrics, quality of care, Medical Expenditure Panel Survey, National Health Interview Survey

Introduction

Effective communication between health care providers and parents contributes to improved pediatric health outcomes. Parent-provider communication and collaboration between health care teams and families are cornerstones of patient- and family-centered care (PFCC) (1). National recognition has been placed on the importance of PFCC through initiatives designed to improve health care quality since the early 2000s (2). To competently deliver PFCC, health care providers should be trained to listen, show respect, explain what caregivers need to know, and spend enough time with patients and families during medical encounters (1). These PFCC qualities are important for parents to gain knowledge, participate in shared decision-making, and be confident in their abilities to care for children with diagnosed health conditions.

In the United States (US), national prevalence estimates of developmental and chronic health conditions have increased over the past several years (3–6). Increased access to health care allows children greater opportunities for chronic

condition diagnosis and treatment, which in turn may allow the patient to avoid needing emergent care (7). For example, many children with developmental delays can receive early childhood intervention therapies early on in their lives to assist them in catching up with their typical peers (8), thereby mitigating reactive treatments later on. However, these therapies can only occur with parental buy-in. If parents do not feel that their perspectives regarding their child's care are being heard and understood by their child's health care providers, or if the parents do not

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understand the need for the therapies, they may not follow through with the recommended treatments. The increasing prevalence of developmental and chronic health conditions makes PFCC critical for parents to appropriately care for their children and make decisions that will affect their children's health later in life.

Previous studies evaluating parents' perceptions of PFCC highlight differences by race/ethnicity, family income level, and health insurance status (9–11). For example, one study found that regardless of primary language (Spanish or English), Latinx parents were less likely to report that the provider spent enough time with them or showed them respect than non-Hispanic Whites (9). Another study reported that parents of poor children were less likely to report their provider showed them respect than those with high incomes (10). Parents of children with public health insurance were less likely to report their provider explained things in a way they could understand compared to those with private health insurance coverage (10).

Although studies have evaluated parents' perceptions of PFCC whose children have been diagnosed with obesity (12), functional limitations, and special health care needs (13, 14), using nationally representative data, few studies have evaluated parents' perceptions of PFCC whose children have been diagnosed with developmental and chronic health conditions. Previous research found that parents of children with any reported health conditions were less likely to report their health care provider exhibited all qualities expected of PFCC (listened carefully, explaining things, showed respect, and spent enough time with them) (15). Moreover, parents whose children had any development or chronic conditions were less likely to report their health care provider always explained their child's care thoroughly compared to those whose children did not have any conditions (15). There remains a gap in the literature on how PFCC differs for children with specific developmental and chronic conditions (e.g., allergies, asthma, autism, attention-deficit/hyperactive disorder [ADD/ADHD], and developmental delays) using nationally representative data and how other contributing factors play a role in associations between health condition prevalence and PFCC.

The theoretical frameworks guiding our current study include the family systems theory (16) and Head and Butte's extension to Street's ecological model (17–19). Family systems theory investigates the interactive and complex system that creates a family, and therefore a family's communication patterns (16). The organization of family relationships, beliefs, and cognitions, and communication processes shared are useful when examining communication about pediatric health needs (16). Recent research shows the impact of the family system on health communication practices between patients, family members, and health care providers (20, 21). Family communication patterns can present both opportunities and challenges for pediatric patients with chronic or developmental health conditions in particular, especially as they learn to navigate the health

care system on their own as they become adolescents and later, adults (22). Third parties, such as family members, in health care interactions, merit further investigation as little scholarly research attends to their influence (17, 20). Currently, what is known shows that parents have communicative influence over their children's health behaviors, with a recent focus on the importance of triadic communication between the patient, their family, and the health care providers (17, 21).

Building from these frameworks and the gap in existing literature, the purpose of this study was to evaluate differences in parents' perceptions of PFCC by their child's health condition status. In this study, parents are evaluated as the third party in health care interactions using these frameworks. Objectives are to (1) estimate and compare the prevalence of PFCC among children with health conditions (e.g., developmental delay, ADHD/ADD, autism spectrum disorder, diabetes, arthritis, asthma, congenital heart disease, or any other heart conditions) and (2) determine associations between the presence of developmental or chronic health conditions and parents' perceptions of PFCC after controlling for covariates.

Methods

Study Design and Data Sources

Our sampling frame comprised of the multiple years of linked cross-sectional data from the National Health Interview Survey (NHIS) and Medical Expenditure Panel Survey (MEPS) data (NHIS 2012–2016; MEPS 2013–2017). Since 1957, the NHIS has collected information on health care services, health-related behaviors, and health status among the civilian noninstitutionalized US adult and child population to monitor trends while tracking progress toward national goals (23). Since 1996, the Agency for Healthcare Research and Quality's (AHRQ) MEPS has collected information on sociodemographic factors, health care utilization, expenditures, and health insurance coverage from nationally representative samples using a survey panel design (24). Households recruited are selected based on a subsample of households who participated in the previous year's NHIS, which allows for linkage of the two data sources to increase sample and provide a broader assessment of child health conditions. For both surveys, information about one child (≤ 17 years old) is collected from a knowledgeable adult in the household. Further details are reported elsewhere (24, 25).

Participants

The sample includes parents of children (aged 0–17 years) who completed both the NHIS sample child and MEPS household component and had a pediatric primary care visit in the last 12 months ($n = 7,835$).

Variables

Predictor Variables. Predictor variables included whether the child had any developmental or chronic health conditions, which were measured using NHIS data. Parents were asked to self-report whether a doctor or other health care professional ever said the sample child had a developmental delay, ADHD/ADD, autism spectrum disorder, diabetes, arthritis, asthma, congenital heart disease, or any other heart conditions. Dichotomous variables (yes or no) were created to represent children who were ever diagnosed with any of the aforementioned conditions. Results for diabetes, arthritis, and all heart-related conditions were not reported due to small sample sizes.

Outcome Variables. Outcome variables included parents' perceptions of PFCC demonstrated by the child's health care provider in the last 12 months, which were measured using MEPS data. Parents ranked how often their health care provider: listened carefully; explained things clearly; showed them respect; and spent enough time with them using a 4-point Likert scale (1 = never, 2 = sometimes, 3 = usually, 4 = always). Responses to each question were dichotomized to "always" or "not always" based on the skewness of responses and small sample sizes when we evaluated each developmental and health condition separately. Responses were positively skewed toward "4 = always." This method has been used by previous studies (15, 26). Each PFCC domain was evaluated separately. Using these questions on PFCC from MEPS, a combined measure of PFCC quality was created to determine parents' reports of whether their child's health care provider always demonstrated all domains of PFCC quality.

Covariates. Based on our theoretical approach and previous studies, covariates that were examined included child age (0–5 years, 6–10 years, 11–17 years), sex, race/ethnicity (Hispanic, Non-Hispanic White, Non-Hispanic Black, and Non-Hispanic other/multiple race), family income based on the federal poverty level (<200% or \geq 200%), health insurance (private, public, none), and perceived health status (fair/poor or good/very good/excellent).

Data Analysis. We calculated weighted percentages and standard errors for selected characteristics of children for each developmental and chronic condition. Bivariate analyses were conducted to determine differences in PFCC among children with and without each developmental or chronic health condition. Comparisons were made for each PFCC domain separately and the combined measure of PFCC quality. Chi-square tests ($p < 0.05$) were used to determine statistically significant results for all categorical comparisons. Crude and adjusted logistic regression procedures were used to determine associations between the presence of each developmental or chronic health condition and parents' perceptions of PFCC after controlling for confounders. Data

were analyzed using STATA 16.0 survey procedures (SVYSET). The combined, linked dataset was analyzed at the Dallas–Fort Worth Federal Statistical Research Data Center with approval from the AHRQ.

Results

Overall, 37.3% of children had any developmental or chronic health condition comprising of ADD/ADHD, allergies, arthritis, asthma, autism, diabetes, developmental delays, diabetes, or any heart condition. The most common health conditions reported were asthma (14.2%) and allergies (13.2%). The prevalence of childhood ADD/ADHD, developmental delays, and autism were 9%, 4.5%, and 2%, respectively. Any heart conditions, arthritis, and diabetes results were not reported due to small samples.

Selected Characteristics

Selected characteristics of children by developmental or chronic health condition are presented in Table 1. Results are presented for the child whose parents reported "yes" for each developmental or chronic health condition. For all developmental or chronic health conditions, the highest prevalence was found among children aged 11–17 years old. Children with ADD/ADHD were more likely to be older (72.1% aged 11–17 years; $p < .0001$), male sex (69.9%; $p < 0.0001$), non-Hispanic White race (62.4%; $p < 0.0001$), have private health insurance (55%; $p = 0.0032$), and have lower family income (58.4%; $p = 0.0106$). Statistically significant differences were found among children with and without allergies by age ($p = 0.0279$) and race/ethnicity ($p < 0.0001$). Children with asthma were more likely to be older (57% aged 11–17 years; $p < 0.0001$), male sex (58.2%; $p < 0.0001$), non-Hispanic White race (47.7%; $p < 0.0001$), have private health insurance (57%; $p = 0.0002$), have lower family income (59.3%; $p = 0.0017$). Statistically significant differences were found among children with and without autism by age ($p < 0.0001$) and sex ($p < 0.0001$). Most children with developmental delays were male sex (66.6%) ($p < 0.0001$). For all developmental or chronic health conditions, most children had reports of good, very good, or excellent perceived health status (all p 's < 0.05).

Bivariate Results

Bivariate results comparing PFCC for each developmental and chronic health condition are reported in Table 2. Results are presented for the child whose parents reported "yes" for each developmental or chronic health condition and "always" for the PFCC quality composite measure and specific PFCC domains. Statistically significant differences were found when we compared perceptions of PFCC quality using the composite score among parents of children with autism ($p = 0.0428$) and developmental delays ($p = 0.0038$). Statistically significant differences were found

Table 1. Selected Characteristics of Children with Developmental or Chronic Conditions, n = 7,835.^a

	ADD/ADHD n = 548 % (SE)	Allergies n = 1,028 % (SE)	Asthma n = 1,211 % (SE)	Autism n = 145 % (SE)	Developmental delay n = 347 % (SE)
Age					
0–5 years	1.9 (0.00)*	32.3 (0.00)*	10.3 (0.00)*	26.1 (0.00)*	25.5 (0.00)
6–10 years	26.0 (0.00)*	31.2 (0.00)*	32.7 (0.00)*	29.7 (0.00)*	34.1 (0.00)
11–17 years	72.1 (0.00)*	36.5 (0.00)*	57.0 (0.00)*	44.3 (0.00)*	40.4 (0.00)
Sex					
Male	69.9 (0.01)*	50.4 (0.00)	58.2 (0.00)*	81.4 (0.00)*	66.6 (0.00)*
Female	30.1 (0.00)*	49.6 (0.00)	41.8 (0.00)*	18.6 (0.00)*	33.4 (0.00)*
Race/ethnicity					
Hispanic	14.4 (0.00)*	20.4 (0.00)*	20.6 (0.00)*	15.3 (0.00)	17.4 (0.00)
Non-Hispanic white	62.4 (0.01)*	43.3 (0.00)*	47.8 (0.01)*	63.0 (0.00)	52.4 (0.00)
Non-Hispanic black	15.8 (0.00)*	17.9 (0.00)*	20.7 (0.00)*	11.9 (0.00)	12.5 (0.00)
Non-Hispanic other/multiple	7.7 (0.00)*	18.4 (0.00)*	10.9 (0.00)*	9.8 (0.00)	17.7 (0.00)
Health insurance					
Any private	55.0 (0.00)*	62.9 (0.00)	56.9 (0.01)*	63.4 (0.00)	61.0 (0.00)
Public only	42.8 (0.00)*	34.7 (0.00)	41.3 (0.00)*	33.4 (0.00)	37.8 (0.00)
Uninsured	2.2 (0.00)*	2.4 (0.00)	1.8 (0.00)*	3.2 (0.00)	1.2 (0.00)
Family income (poverty level)					
<200%	58.4 (0.00)*	64.4 (0.01)	59.3 (0.01)*	66.0 (0.00)	61.8 (0.00)
200% or greater	41.6 (0.00)*	35.6 (0.00)	40.7 (0.00)*	34.0 (0.00)	38.2 (0.00)
Perceived health status					
Poor/fair	4.4 (0.00)*	3.3 (0.00)*	4.7 (0.00)*	10.9 (0.00)*	9.2 (0.00)*
Excellent/very good/good	95.6 (0.01)*	96.7 (0.01)*	95.3 (0.01)*	89.1 (0.00)*	90.8 (0.00)*

Note: ^aData are linked from 2012–2016 National Health Interview Survey (NHIS) and 2013–2017 Medical Expenditure Panel Survey (MEPS). ADD/ADHD = attention-deficit/hyperactive disorder.

* $p < 0.05$.

Table 2. Bivariate Analysis for each Measure of Parents' Perceptions of Patient- and Family-centered Care (PFCC) by Child Health Condition, n = 7,835.^a

	ADD/ADHD % (SE)	Allergies % (SE)	Asthma % (SE)	Autism % (SE)	Developmental delay % (SE)
PFCC quality composite	64.6 (0.00)	67.0 (0.00)	70.0 (0.01)	58.3 (0.01)*	59.7 (0.00)*
PFCC domains					
Listened carefully	80.1 (0.01)	78.7 (0.00)*	82.3 (0.01)	71.2 (0.00)*	73.2 (0.00)*
Explained clearly	77.1 (0.01)*	82.4 (0.00)	83.5 (0.01)	77.4 (0.00)	78.7 (0.00)
Showed respect	81.9 (0.01)	85.2 (0.00)	86.5 (0.01)	78.1 (0.00)	82.9 (0.00)
Spent enough time	77.2 (0.01)	77.7 (0.00)	79.4 (0.01)	69.3 (0.00)	74.5 (0.00)

Note: ^aData are linked from 2012–2016 National Health Interview Survey (NHIS) and 2013–2017 Medical Expenditure Panel Survey (MEPS). ADD/ADHD = attention-deficit/hyperactive disorder.

* $p < 0.05$.

when we compared specific PFCC domains by condition status. Among children with ADD/ADHD, 77.1% of parents reported their health care provider always explained things clearly ($p = 0.0234$). Parents of children with allergies (78.7%), autism (71.2%), and developmental delays (73.2%) were more likely to report their health care provider always listened carefully (all p 's < 0.05).

Multivariable Results

Multivariable logistic regression results are reported in Table 3. In adjusted models, no statistically significant

differences were found when we evaluated PFCC quality using the composite measure or for each specific PFCC domain when we evaluated parents of children with any health condition, evaluated as a combined measure for children who reported having ADD/ADHD, allergies, arthritis, asthma, autism, diabetes, developmental delays, diabetes, or any heart condition. However, when we evaluated PFCC for each condition specifically, parents of children with developmental delays had 32% lower odds (95% CI = 0.51–0.90) of reporting their health care provider always provided all PFCC qualities. No statistically significant results were found when comparing PFCC quality as a composite

Table 3. Multivariable Logistic Regression Models Examining Associations Between Each Child Health Condition and Parents' Perceptions of Patient- and Family-centered Care (PFCC), n = 7,835.^{a,b}

	PFCC quality composite OR (95% CI)	PFCC domains			
		Listened carefully OR (95% CI)	Explained clearly OR (95% CI)	Showed respect OR (95% CI)	Spent enough time OR (95% CI)
ADD/ADHD					
No	1.00	1.00	1.00	1.00	1.00
Yes	0.82 (0.64–1.05)	0.89 (0.64–1.22)	0.74 (0.56–0.99)*	0.76 (0.55–1.05)	0.88 (0.65–1.20)
Allergies					
No	1.00	1.00	1.00	1.00	1.00
Yes	0.89 (0.73–1.08)	0.74 (0.58–0.95)*	0.92 (0.72–1.19)	0.93 (0.74–1.18)	0.95 (0.75–1.19)
Asthma					
No	1.00	1.00	1.00	1.00	1.00
Yes	1.12 (0.91–1.37)	1.08 (0.86–1.35)	1.15 (0.92–1.44)	1.09 (0.85–1.40)	1.11 (0.88–1.40)
Autism					
No	1.00	1.00	1.00	1.00	1.00
Yes	0.66 (0.42–1.04)	0.59 (0.34–1.02)	0.81 (0.45–1.45)	0.61 (0.34–1.08)	0.65 (0.39–1.08)
Developmental delay					
No	1.00	1.00	1.00	1.00	1.00
Yes	0.68 (0.51–0.90)*	0.58 (0.42–0.80)*	0.80 (0.57–1.12)	0.81 (0.56–1.15)	0.82 (0.59–1.13)

Note: ^aData are linked from 2012–2016 National Health Interview Survey (NHIS) and 2013–2017 Medical Expenditure Panel Survey (MEPS).

^bAdjusted for age, sex, race/ethnicity, insurance, family income federal poverty level, and perceived health status. ADD/ADHD = attention-deficit/hyperactive disorder.

*p < 0.05.

measure among children with and without ADD/ADHD, allergies, asthma, or autism. When separated by specific PFCC domains, fewer parents perceived their health care providers always listened carefully and explained things clearly. However, when we evaluated each PFCC domain separately, parents of children with allergies and developmental delays had 26% and 42% lower odds of reporting their health care provider always listened carefully compared to parents whose children did not have those conditions. Parents of children with ADD/ADHD had 26% lower odds (95% CI = 0.56–0.99) of reporting their health care provider always explained things clearly compared to parents of children who did not have ADD/ADHD. No statistically significant differences were found for the PFCC domains of showing respect or spending enough time for any developmental or chronic health conditions.

Discussion

The purpose of this study was to evaluate differences in parents' perceptions of PFCC by their child's health condition status based upon family systems theory research and recent recommendations to explore third parties as part of the ecological model (17, 19, 21). Overall, we did not find any statistically significant differences in parents' perceptions of PFCC quality whose children had any developmental or chronic health condition. Nevertheless, when we evaluated each condition separately, we found that PFCC qualities differed most among parents whose children had ADD/ADHD, allergies, and developmental delays who reported poorer PFCC than parents whose children were not diagnosed

with these specific health conditions. Our results align with the findings of other nationally representative studies which have found that parents whose children have been diagnosed with obesity (12), functional limitations, and special health care needs (13, 14) experience poorer PFCC than those whose children did not have those health conditions.

Many caregiving adjustments must be made by parents for children with ADD/ADHD, allergies, and developmental delays. If parents do not feel they are being carefully listened to, or that things are explained well, their child's care can be affected negatively. It could be that ADD/ADHD, allergies, and developmental delays are not perceived as generally serious conditions requiring lengthy explanations, or that practitioners assume that other members of the health care team are able to engage with the family members regarding questions. For example, children with developmental delays often have a team of providers that include the pediatrician, nurses, early childhood intervention specialists, speech therapists, occupational therapists, and more. Regardless, health care providers should make efforts to ensure parents perceive they are being listened to carefully and that things are explained to them as there are implications for health care outcomes. For example, if health care providers explain the need for specialists (e.g., occupational therapists) rather than simply providing a referral, the parents may be more likely to seek care for their child. Further, families of children with food allergies must evaluate whether to avoid the allergen or to engage in oral desensitization, particularly if the allergy is severe or if the allergen is common (i.e., milk, eggs) (27, 28). After a diagnosis of food allergies, a family may need referrals to educational programs with

health care providers to increase their knowledge and improve their health outcomes (29).

Limitations

Some limitations in our approach should be noted. First, we evaluated parents' perceptions of their interactions with their health care provider as a whole, rather than separating by father and mother for children in two-person households. As mothers often attend medical appointments and communicate with health care practitioners more frequently than fathers in two-parent households, there may be some gender differences worth exploring (30). Second, while linking the MEPS and NHIS data together is a great strength of the study, the cross-sectional nature of the study makes determining causality difficult. Third, it is difficult to determine from health surveys which treatment team member (e.g., physician, nurse practitioner, physician assistant, or other) was considered the "health care provider." Primary studies should be conducted using qualitative and mixed methodologies to confirm and further explain quantitative findings from secondary research. Fourth, we evaluated parents' perceptions of PFCC as a dichotomous measure to account for the skewness of the data and to ensure sample sizes were large enough for each health condition evaluated. Future studies should provide a more in-depth analysis of the Likert scale data as they were measured to further explain how disparities in race, ethnicity, gender, socioeconomic status, and language can influence parents' perceptions of PFCC in diverse pediatric patient populations. Fifth, we adjusted for the same covariates for each health condition we examined. This method was used for consistency and to compare our results across health conditions. However, some covariates (e.g. age, sex, or race/ethnicity) may be more influential when examining some health conditions over others.

Implications

Research shows the need for patient- and family-centered interventions for children with special health care needs to improve health care outcomes (1). Our findings can inform the development of such interventions by demonstrating the importance of tailoring communication to meet the needs of families who have children with ADD/ADHD, allergies, and developmental delays in particular using family systems theory and the ecological approach as theoretical frameworks (17, 19, 21). Since PFCC systems are associated with decreased family burden and more efficient health care use for children with special health care needs (31), it is important for health care providers to engage patients with chronic health conditions like ADD/ADHD, allergies, and developmental delays with regular opportunities to build a true partnership (i.e., through careful listening, spending enough time) with the entire health care team. Health care education should also encourage the centering of PFCC in trainings and programs for health care practitioners.

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Declaration of Conflicting Interests

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Ethical Approval

Ethical approval is not applicable for this it included secondary data that were anonymous and de-identified; therefore, it was not considered human subjects' research by the University of Texas at Arlington Institutional Review Board.

Statement of Informed Consent

Informed consent for patient information to be published in this article was not obtained because it included secondary data previously collected.

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