

Influence of pediatric patients' developmental or chronic health condition status
as a predictor of parents' perceptions of patient-
and family-centered care

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Abstract

Our study aimed to estimate how a pediatric patient's health condition status influences parents' perceptions of patient- and family-centered care (PFCC). We analyzed five years (2013–2017) of Medical Expenditure Panel Survey data in efforts to expand understanding of the family influence in pediatric health encounters, using family systems theory as our theoretical lens. The sample included 36,675 parents of children with developmental or chronic health conditions who reported visiting a health care provider within the past 12 months. The independent variable was a combined measure of any developmental or chronic health conditions previously diagnosed in the child being assessed. Dependent variables included parent reports of communication variables related to how often providers: listened; showed respect; spent enough time; and explained things well. Multivariable logistic regression was used to evaluate the odds of receiving PFCC using a dichotomous measure of PFCC quality and separate domains. Results found that 1) the dichotomous variable of PFCC showed that parents of children with health conditions were less likely to report their provider always performed all elements of PFCC compared to parents whose children did not have any health conditions; 2) parents of children with developmental or chronic health conditions were less likely to report their provider always explained things well compared to parents whose children did not have any health conditions. Efforts to improve PFCC should focus on training providers to demonstrate high quality practices to improve health outcomes for pediatric patients with developmental or chronic conditions.

Keywords: patient- and family-centered care; pediatric chronic illness; Medical Expenditure Panel Survey; triadic communication

Communication is central to the health care interactions between patients, families, and clinicians (Street, 2013). More specifically, the communication occurring between physicians, parents of children with developmental or chronic health conditions, and the patients themselves (patient- and family-centered care [PFCC]) is of the utmost importance for pediatric health outcomes (LaDonna et al., 2017). PFCC is based on the idea that a child's primary source of strength and support in managing their care originates from the family (Committee on Hospital Care, 2003). Since chronic health conditions arguably place the most burden on the United States' health care system, they are particularly important to examine (McPhail, 2016). Estimates of childhood developmental disabilities and chronic conditions such as diabetes, asthma, arthritis, and congenital heart conditions continually increase year to year (Zablotsky et al., 2017). The Institute of Medicine (IOM) reported four important components of quality health care: safety, effectiveness, patient-centeredness, and timeliness (Institute of Medicine (US) Committee on the National Quality Report on Health Care Delivery, 2001). While patient-centered care primarily focuses on the patient, recommendations include an increased focus on family members (Epstein & Street, 2007).

Family systems theory examines how families function as a complex and interacting system and will provide the theoretical lens through which the study is examined (Pratt & Skelton, 2018). One model in particular exemplifies the importance of communication in medical encounters: Street's ecological model (Street, 2003). Unfortunately, the triadic dynamics of communication between health care providers, the patient, and the family within the medical setting have continued to receive little attention from scholarly research (Eldredge et al., 2014; Head & Bute, 2018). Specifically, recent research calls for a reconceptualization of the role of third parties in the ecological model (Head & Bute, 2018). Therefore, this study will bridge the

aforementioned gap in the present research and use cross-sectional, nationally representative data to evaluate differences in parents' perceptions of PFCC by their child's health condition status. The present study aims to 1) estimate and compare the prevalence of PFCC among children with developmental or chronic health conditions and without health conditions, and 2) determine associations between the presence of developmental or chronic health conditions and parents' perceptions of PFCC before and after controlling for confounders and other explanatory factors.

Literature Review

Research qualitatively shows that chronic and progressively degenerative conditions provide challenges in providing patient-centered care (LaDonna et al., 2017). When the patient is a child, however, even more challenges arise including negotiating shared decision-making (Hanson et al., 2017), end-of-life care (Yu et al., 2019), and the evolvment of a child into a young adult (Schlucter, 2014). Other barriers to implementing PFCC include a lack of understanding of what family-centered care is, support for practices (inadequate insurance, family financial difficulties, employment constraints), and a lack of research (Kuo et al., 2012). Yet, one scoping literature review of twelve studies reports PFCC as a predictor for improved patient and family experiences (DeRosa et al., 2019). Another review of systematic reviews on PFCC found that PFCC has the potential for dramatically improving the quality of health care (Park et al., 2018). PFCC is promising, yet has complex layers; specifically, the family.

Research shows that quality triadic communication between health care providers, patients (often minors), and a third party (often parents of minor children) is vital in achieving improved health outcomes (Street, 2013). 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 health later in life (Pallapies, 2006). For children with

chronic illnesses, such as diabetes or asthma, this is of particular importance as they will need care regularly for the rest of their lives. For example, research shows that parents of children with type 1 spinal muscular atrophy, a chronic condition, value strong family/provider partnerships, feeling heard and respected by their providers, and receiving complete education regarding disease trajectory (Murrell et al., 2018). Further, at some point their care will transfer from pediatric specialists to the adult context, at which time their perceptions of health care based in childhood can affect their health care-seeking behaviors, as well as health outcomes, later in life (Schlucter, 2014). Therefore, it is vital for pediatric patients with chronic health conditions to experience quality triadic communication.

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 to improve PFCC (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012). Family communication needs for children with chronic health conditions can vary by family, yet many have similarities. For example, one systematic literature review found that health care providers who show respect for each child's patient needs and preferences can create a stronger collaborative approach towards managing health outcomes (Kuo et al., 2012). Similarly, other research establishes that open-ended questions by the health care provider are a best practice in improving open communication, which can in turn help health care providers assess what the caregivers may need to know and where their understanding is lacking (October et al., 2016). These qualities of PFCC are vital for parents to gain knowledge, participate in shared decision-making, and be confident in their abilities to care for children with diagnosed health conditions (Kobussen et al., 2020).

Patient-centered care can help inform what patients and families value in PFCC. For example, patients receiving care for cancer want to be understood and feel heard by physicians who respond to their questions and exhibit both empathy and sensitivity (Mazor et al., 2013). For patients admitted to the pediatric ICU, parental satisfaction with a physician's patient-centered care is influenced positively by an increased level of empathy and questions asked by the physician to the patient (October et al., 2016). Parents of hospitalized children may feel that even though they are included in discussions of care, communication with multiple doctors can be confusing, pointing to the importance of a cohesive health care team with a clear plan for communicating information to parents and patients (Uhl et al., 2013). While some models address the importance of patient-centered care, PFCC is less understood (Park et al., 2018).

Interpersonal Communication in Health Care Encounters

One model clearly demonstrating the importance of communication between health care provider and patient is Street's ecological model (Street, 2003). Street (2003) considers many factors that may affect interpersonal communication between patients and their health care providers, including one's culture. Research shows there are both predisposing influences and cognitive-affective influences that affect both the patient and provider's verbal and nonverbal behavior (Street, 2003; 2013). Predisposing influences include communication style, attitudes, and beliefs; cognitive-affective influences include perception of communication partner/relationship, goals, and communicative strategies (Street, 2003). However, Head and Bute (2018) argue that a fifth outside context is necessary to consider when discussing interpersonal communication between health care providers and patients. This additional context is the everyday interpersonal context, meaning how family, friends, or peers influence communication in medical encounters. For example, the family communicative environment can

significantly influence patient perceptions of the level of involvement patients have in health care, as well as the level of medical adherence and satisfaction with care (Rauscher et al., 2020). Less is known, however, about individuals who may play multiple roles in the medical encounter (e.g., both a third-party at an appointment and simultaneously a source of family support).

Family Systems

Established research demonstrates that the family systems approach is useful in examining how families communicate about health with pediatric patients, specifically through the organization of family relationships, the cognitions and beliefs shared within a family, and family communicative processes (Hagstrom, 2017). Specifically, the family systems approach has informed research examining chronic health conditions such as HIV, depression, and anxiety (Gray et al., 2011), as well as investigating how families navigate stress while their children are in the pediatric intensive care unit (Hagstrom, 2017).

Previous research evaluating parents' perceptions of PFCC acknowledges the presence of several confounding variables, including race, ethnicity, health insurance status, and family income (Anderson et al., 2019; Guerrero et al., 2010). For example, one study evaluated parents' perceptions of PFCC whose children have been diagnosed with special health care needs, finding that several statistically significant disparities exist due to PFCC quality (Bleser et al., 2017). Yet there remains a gap in the literature on 1) how parents' perceptions of PFCC differs for pediatric patients with developmental and chronic conditions and 2) how confounders and other explanatory variables play a role in associations between health condition prevalence and parents' perceptions of PFCC. Therefore, this study aims to address the aforementioned aims in light of the recent call for an expanded understanding of the interpersonal processes in health care encounters (Head & Bute, 2018).

Methods

Participants and Procedures

Medical Expenditure Panel Survey (MEPS). The sample was acquired using the MEPS data (*Medical Expenditure Panel Survey Content Summary of the Household Interview*, n.d.). Since 1996, the Agency for Healthcare Research and Quality's MEPS has collected information on sociodemographic factors, health care utilization, expenditures and health insurance coverage from nationally representative samples using a survey panel design (*Medical Expenditure Panel Survey Content Summary of the Household Interview*, n.d.). The survey tracks national trends as well as progress towards national goals. Households recruited are selected based on a subsample of households who participated in the previous year's NHIS. The panel design includes five face-to-face interviews and self-administered questionnaires collected over a span of two years.

The sample for this study included parents of children ages 0-17 who visited a primary care provider within the last 12 months from the date of data collection. Questions about one eligible child (<17 years old) were answered by a knowledgeable adult in the household. Using several years (2013-2017) of nationally compiled data provided a more representative sample with a greater sample size ($n=36,675$), including minority populations that would otherwise be underrepresented in a smaller sample collection. After completion of the household interviews, medical providers are contacted by telephone to provide additional details on diagnostic codes.

Measures

Dependent Variable. The dependent variables were parents' ratings of their PFCC exhibited by their child's provider. Using a Likert scale (1=never, 2=sometimes, 3=usually, 4=always), parents rated how often their child's health care provider in the last twelve months: listened carefully, explained their child's care plan thoroughly, showed them respect, and spent

enough time with them during their visit. The “Never”, “Sometimes”, and “Usually” responses were combined into dichotomous measure to compare parents that “Always” or “Not Always” reported each quality based on the distribution and skewness of data in the final sample (Kindratt et al., 2020).

Independent Variable. The independent variable assessed in this study was the presence of any developmental or chronic health conditions previously diagnosed in the child being assessed. MEPS data regarding the child’s health status was collected from medical condition files. Any CCC, ICD-9-CM, or ICD-10-CM codes attached to the records of the clinic visits qualified the child as having a specific health condition diagnosis. A composite variable was used to combine children diagnosed with a developmental or chronic health conditions to those with no documented health conditions. The medical records of the children being surveyed were screened for the presence of nine specific ICD-9-CM codes (250, 477, 493, 202, 590, 473, 692, 401) and five CCC codes (043, 083, 654, 115, 253, 203) in the data compiled between 2013-2015. ICD-9-CM codes were converted and streamlined to be more efficient and descriptive when coding medical information following the implementation of the final phase of the Health Information Portability and Accountability (HIPAA) Act in 2014 (Cartwright, 2013). As this was a retrospective data collection, the data collected was relevant to the calendar year preceding. Data from 2015-2017 used eighteen different ICD-10-CM Codes (C80, E11, F80, F84, G31, G89, I10, I34, I35, J30, J32, J45, L23, M06, M16, M17, M19, N18).¹ Seven yes-no categories were also used to categorize common pediatric diagnoses: diabetes, asthma, allergies, any heart condition, arthritis, and finally the- combination of any developmental delays (autism, ADD, and ADHD included) into one category due to small sample sizes.

¹Table further explaining ICD-9/CCC an ICD-10 Codes available upon request from the authors.

Covariates. Other variables also assessed included child age (0-5, 6-10, 11-17 years), child sex, race/ethnicity, (non-Hispanic White, Hispanic, non-Hispanic Black, non-Hispanic Asian, non-Hispanic Other/Multi-Race), nativity status (born or not born in the United States), language spoken at home (English, Spanish), health insurance coverage (any private, public only, uninsured), whether or not the child had a usual source of health care they saw regularly, family income (family percentage of poverty level), perceived health status (excellent, very good, good/fair/poor), parent and mental health status (excellent, very good, good/fair/poor), and whether or not the child had special health care needs, such as limited or prevented in in ability to do the things most children of the same age can do or needs special therapy for physical, occupational, medical or behavioral concerns.

Statistical Analysis. Using STATA v. 16.0, researchers merged five years (2013-2017) of MEPS data files, combining the household and medical condition files. Frequencies (unweighted) and percentages (weighted) were presented for child's health condition status and sociodemographic characteristics by the PFCC dichotomous measure and each domain of PFCC quality. Statistically significant differences were tested using chi-square tests. Crude and multivariable logistic regression models were used to examine associations between the PFCC variables and the combined measure of a child's health condition status before and after controlling for confounders and other explanatory variables. Associations were examined for the dichotomous measure of PFCC quality and each separate PFCC domain. Purposeful selection methods were used selecting variables for the fitted multivariable model (Hosmer et al., n.d.). Effect measure modification was examined for all covariates using Wald tests ($p < .05$) to determine significant interactions. Significant interaction results were stratified, and 95%

confidence intervals were compared. Intuitional review board approval was not needed as the study examined deidentified, publicly available national data.

Results

Selected Characteristics

From 2013-2017, 18.6% of participants had a developmental or chronic health condition. Among parents who reported their health care professionals always provided PFCC, 20.5% had a developmental or chronic health conditions. Children whose parents reported the health care professionals always provided PFCC were more likely to be non-Hispanic white (53.9%), speak English (90.7%), have private health insurance (62.6%), have a family income \geq 400% of the federal poverty level (33.1%) (all $p < .05$). Furthermore, over half children whose parents reported their providers always provided PFCC had excellent perceived health status (59.9%), mental health status (63.1%), and no other special health care needs (78.2%) (all $p < .05$). Characteristics of children whose parents reported their health care providers always exhibited each separate quality of PFCC are presented in Table 1.

(Insert Table 1 Here)

Logistic Regression Results

In crude models, parents of children with a developmental or chronic health conditions had 16% lower odds (OR=0.84; 95% CI=0.76-0.94) of reporting their health care provider always demonstrated PFCC during their appointments compared to parents who children did not have any a developmental or chronic health conditions. Results remained statistically significant after adjusting for demographic (child sex, child age, child race/ethnicity, language spoken at home), family income, health insurance coverage and access to health care (OR=0.84; 95% CI=0.75-0.93). The only statistically significant association was found between child health

condition status and parents' perceptions of whether their health care provider always explained things in a way they could understand. Parents of children with health conditions had 12% lower odds (OR=0.88; 95% CI=0.79, 0.99) of reporting their provider always explained things compared to parents whose children did not have a developmental or chronic condition. Other crude and adjusted logistic regression results for each separate quality of PFCC are presented in Table 2.

(Insert Table 2 here)

Interactions

Among children without any special health care needs, parents of children with developmental or chronic health conditions had 20% lower odds (OR=0.80; 95% CI=0.70-0.91) of reporting their health care provider always demonstrated PFCC during their appointments compared to parents whose children did not have any developmental or chronic health conditions. Furthermore, among children without any special health care needs, parents of children with developmental or chronic health conditions had 14% lower odds (OR=0.84; 95% CI=0.75-0.98) of reporting their health care provider always spent enough time with them during their appointments compared to parents whose children did not have any developmental or chronic health conditions. No other significant interactions were observed.

Discussion

The goals of this study were to 1) estimate and compare the prevalence of PFCC among children with developmental or chronic health conditions, and 2) determine associations between the presence of any developmental or chronic health conditions and parents' perceptions of PFCC before and after controlling for confounders. Further, this study aimed to apply these findings within the call for further research in the interpersonal context of clinical encounters

(Head & Bute, 2018). Overall, this study demonstrated three key findings: 1) Parents whose children had a developmental or chronic health condition were less likely to report their health care provider exhibited all qualities of PFCC compared to those whose children did not have any developmental or chronic health conditions; 2) when we examined each domain separately, parents whose children had a developmental or chronic health condition were less likely to report their health care providers explained things in a way they could understand compared to those who did not have any health conditions; and 3) parents whose children had a developmental or chronic condition but no other special health needs reported health care providers were less likely to spend enough time with them.

Patient- and Family-Centered Communication

The composite variable of PFCC (listening, explaining, showing respect, and spending time) showed a significant association with pediatric developmental or chronic health conditions. Our findings therefore confirm previous research finding that most parents in the United States generally feel that their children receive high-quality care from their children's health care providers (Bleser et al., 2017; Romaine & Bell, 2010). Since previous research reports that people with chronic illnesses indicate that their family members play significant roles in how they communicate with health care providers (Head & Bute, 2018), it is likely that this is even more amplified when the patient is a minor. However, perceptions of high-quality care from one's health care providers is shown to have varied results based on demographics (DeVoe et al., 2009). In our study, we found that the parents who reported health care professionals always provided PFCC were more likely to be non-Hispanic white, which confirms previous research.

Because previous research demonstrates varied results using the composite variable approach (Kindratt et al., 2020) we then individually tested each element of PFCC to further

investigate the associations between pediatric health conditions and how often providers listened; explained things; showed respect; and spent enough time with the patients. In the present study, parents of children with developmental or chronic health conditions were less likely to report their provider always explained things compared to parents whose children did not have any health conditions. Other research found that providers explaining all options was among the least likely variable examined significantly associated with unmet health care needs in the following year (Lindly et al., 2017). These same researchers recognized that one limitation to the item itself is that family members may not always be able to accurately judge if or whether all treatment options were actually explained; rather they may make assumptions based on their existing knowledge. Therefore, while our research echoes previous findings, context should be addressed.

Given that many pediatric patients with chronic health conditions see their health care providers regularly, health care providers may make inaccurate assumptions about what the patient may know (Schlucter, 2014). Alternatively, the parents of the children with health conditions may not know which questions to ask or how to communicate effectively about their child's health condition, particularly given the lack of lived experiences that the parents may have regarding the health condition. The questions parents do have may be withheld for fear of being imposing; providers can show support for parents by asking them about their learning needs and preferences (Nightingale et al., 2015). Therefore, parental reports of PFCC may not fully encapsulate what is actually quality communication. For those with special needs beyond a developmental or chronic condition, there are even more areas of concern.

Beyond Developmental or Chronic Status to Special Health Care Needs

The interactions of special health care needs and any developmental or chronic health condition status were also probed. In this analysis, we found that parents of children with a

developmental or chronic health condition but no special health care needs were less likely to report that their providers always demonstrated all qualities of PFCC during appointments compared to patients who had neither a developmental or chronic health condition or special health care needs. Given that pediatric patients with developmental or chronic health issues are likely to need more regular appointments (including with a variety of specialists) than patients without these health issues (Dewan & Cohen, 2013), this is a problematic finding. While the increased number of appointments might allow for future opportunities for practitioners to communicate with their patients (and families), health care providers should be careful not to rely on these as a substitute for quality PFCC. Further, children with developmental or chronic conditions often see multiple specialists, making communication between practitioners even more complex and increasing the chance for medical errors (Simon et al., 2010). Regardless of the reasoning, special care should be taken, and alternative communicative methods including telehealth considered in aims of increasing parents' reports of PFCC.

Further, our results also found that the parents of pediatric patients with developmental or chronic health conditions but no special health care needs also were less likely to report their providers spent enough time with them compared to the parents whose children did not have either. Feeling that appointments do not last long enough can create barriers to adhering to future appointments, potentially complicating health care and outcomes. One research study qualitatively examined the patient-indicated preferred appointment length (5, 10, 15, or 20 minutes compared with the standard 10-minute appointment) found that patients choosing their preferred appointment length was associated with increased perceived patient empowerment and confidence by the patients (Sampson et al., 2013). This type of appointment scheduling practice may be a one option for practitioners who wish to increase PFCC specifically regarding time

spent with patients. We also found that providers were more likely to spend time with pediatric patients who had both special health care needs and the developmental or chronic health condition status than pediatric patients without special health care needs who had a developmental or chronic health condition status. Previous research shows that having too little time during appointments in which to discuss the complex issues of chronic conditions create barriers for pediatric patients, particularly as they begin to transition out of pediatric and into adult health care systems (Leake et al., 2020; Lindsay et al., 2016). Because certain medical conditions require more time in appointments, the combination of both the health care needs and health conditions status may simply inherently be the cause of the reports of increased time at the appointments. Yet, future research should probe as to how the communication may be a dependent variable of time spent at the appointment(s), as time itself may not always be an indicator of quality communication.

Patient- and Family-Centered Care

Further, considering Head & Bute's (2018) call for an increased focus on the everyday interpersonal context on the interactions within the medical setting, the aforementioned finding is considerably problematic. Given that communication is a learned behavior, pediatric patients with chronic illnesses who have parents who do not perceive high levels of PFCC across each of the elements may not be able to develop positive patient-practitioner communicative skills. Since family systems theory shows that dynamic and constant communication patterns within the family can present both opportunities and challenges for a patient (Crowley & Miller, 2020), it is absolutely vital that the family system recognize the great influence that parents may have on their child's future communication patterns. While parents often perform many roles in coordinating care, including maintaining educational access, at some point many pediatric

patients with chronic health conditions will become their own advocate (White & Cooley, 2018). Being unable to observe *how* and *in which ways* one should communicate with a health care team to achieve optimal health outcomes, particularly for those with lifelong health issues, can set up children for failure. As they age, and learn to navigate the health care system on their own, children with chronic health issues and special health conditions already face several barriers to achieving care that children without special health conditions do not (Schlucter, 2014). In light of such research, health care practitioners should carefully manage how they perform PFCC.

Limitations and Future Directions

The present study is particularly unique because nationally representative data sources were used in response to specific calls for future research of the interpersonal context in health (e.g., Head & Bute, 2018). The strength of using MEPS data is that it is a national survey capable of providing a large, nationally representative dataset to analyze, yet future research should continue examining demographics who historically report disparities due to socioeconomic or other statuses. While there were several limitations to our approach, these limitations do provide context and future directions for extended research. For example, while the sample is nationally representative, there was an over-inflated response for parents who perceived their providers were “good” based on the reports that they “always” listened carefully, explained things, spent enough time, or showed respect. based upon participants’ reports of perceptions of provider care. Future research should seek to include participants who may not, statistically, have a positive experience with providers. For example, the sample used in this study included participants with high incomes, health insurance coverage, and a large number of Caucasian participants, all of which could contribute to the over-reporting of providers who displayed PFCC. Having health insurance, for example, is shown as a positive predictor of communication (DeVoe et al., 2009).

Another factor to consider is geography, as access to health care is often more limited in rural than urban areas (Yehya & Dutta, 2015). Future research should examine underserved populations as the results may be radically different – such as negative evaluations of providers or much more infrequent perceptions of PFCC use.

Further, while several years of data were reported in the present study, causality cannot be claimed. The measures used, while reliable and valid, may not get to the full breadth and depth of dimensions of PFCC (Lindly et al., 2017). Future research should continue to critically examine how PFCC is evaluated, particularly in light of research on health disparities, as parents of children from families with only public insurance and/or with an income below the poverty line report lower quality experiences of PFCC (Bleser et al., 2017). Prior research has also suggested critically examining regional differences in social, economic, and health policy may provide insight into disparities of how patients are communicated to and with (Bleser et al., 2017). Finally, the inclusion criteria limited participants based on the definition of “parents.” Varied household make-ups exist, and future research should survey and interview people from these diverse backgrounds who may not have a traditional nuclear family.

Implications

Several practical and theoretical implications exist as a result of this research study. Practically speaking, pediatric health care professionals should improve their usage of PFCC specifically for patients with developmental and chronic health conditions, as parents of children with health conditions report experiencing PFCC less often than parents of children without health conditions. Increased PFCC by health care professionals can lead to increased quality of care and feelings of being heard/listened to by pediatric patients and their parents (Engelen et al., 2012). Previous research demonstrates the importance of identifying patients at risk of reporting

communication difficulties (Beach et al., 2006). Practitioners should be taught to not only assess their patients' levels of health literacy, for example, but also their patients' families, as they are often not merely caregivers but also advocates or protectors (Kon & Morrison, 2018). More strategies for successful implementation of PFCC include virtual site visits and contact with other pediatric hospitals to learn about model PFCC programs, training sessions, using families as educators, nurses as peer mentors, journal clubs, continuous quality improvement, among other strategies (Moretz & Abraham, 2012). Since family systems theory concepts include first- and second-order change, increasing interactions with families can enable long-term behavior modifications (Pratt & Skelton, 2018). Further, as uncertainty can increase familial stress, involving family members in decision-making practices, through listening to their concerns for example, can help parents specifically learn their roles in managing their child's health care (Hagstrom, 2017). Finally, practitioners should also seriously consider including the child as a direct source of knowledge, rather than solely the parent, as recent research indicates that the child and family reports combined can assist professionals in fully understanding and therefore treating a chronic condition in pediatric patients (Tomlinson et al., 2020). Recent family systems literature describes patient education as an integral component of initiatives to improve health care (DeRosa et al., 2019); therefore, child-oriented pamphlets with question prompts, for example, would be one way to include the patient more fully in the health care interaction.

Theoretically, this study extends existing research by increasing the focus on the role of third parties in patient-practitioner encounters. Specifically, this study highlights an acknowledged limitation of Street's (2003) ecological model (Head & Bute, 2018) by addressing the addition of an interpersonal context and an emphasis on the importance of third-party influence on patient-provider communication through family systems theory. We examined the

effect the family (specifically, the parental role) has on how health care professionals communicate during appointments with children who have chronic health conditions. The present study adds one specific contribution to literature: it is probable that parents of children with chronic conditions play multiple roles in the health care context, particularly with the added legal actions a caregiver can take. Some previous research acknowledges partner communication influences, but these “partners” were limited solely to the patient and the practitioner (Street, 2003). By adding a family member to the clinical encounter, these same influences may be present but complicated by the external processes that occur outside of the clinical context simply by merit of the caretaker-child relationship. Therefore, future research should continue to examine the complexities of adding relational others to medical encounters.

Conclusions

Our study revealed that parent reports of the domains of PFCC vary by pediatric health condition. Therefore, our results demonstrate the importance of training health care providers in quality PFCC to improve health outcomes for pediatric patients with developmental and chronic health conditions, particularly in the context of family systems (DeRosa et al., 2019; October et al., 2016) and the ecological model (Head & Bute, 2018; Street, 2003). Future research should examine how PFCC affects the interactions between parents and children while at the child’s medical appointments. Further studies should be conducted to further explore how PFCC is associated with improved health outcomes among children with chronic condition subgroups to identify important qualities for health care providers to exhibit during family and patient interactions.

Acknowledgements:

No acknowledgements.

Declaration of interest statement:

No potential competing interests were reported by the authors.

Funding:

This work was supported by the Research Enhancement Program sponsored by The Office of the Vice President for Research at The University of Texas at Arlington under Grant 270076.

Data Availability Statement:

The data that support the findings of this study are available in the Agency for Healthcare Research and Quality's Medical Expenditure Panel Survey at <https://www.meps.ahrq.gov/>.

These data were derived from the following resources available in the public domain:

Household Component: https://www.meps.ahrq.gov/mepsweb/survey_comp/household.jsp

Medical Provider Component: https://www.meps.ahrq.gov/mepsweb/survey_comp/mpc.jsp

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Table 1: Selected characteristics of children by parents' perceptions of each quality of patient- and family-centered care; Medical Expenditure Panel Survey Data, 2013-2017.

	Listened carefully <i>N (weighted %)</i>	Explained things <i>N (weighted %)</i>	Showed respect <i>N (weighted %)</i>	Spent enough time <i>N (weighted %)</i>
Developmental or Chronic Health Condition*				
No	18,059 (79.2)	18,286 (79.2)	18,889 (79.1)	17,167 (79.2)
Yes	4,618 (20.9)	4,686 (20.8)	4,855 (20.9)	4,373 (20.8)
Sex				
Male	14,361 (51.2)	14,555 (51.3)	15,006 (51.2)	13,634 (51.2)
Female	13,993 (48.8)	14,186 (48.7)	14,637 (48.8)	13,360 (48.8)
Age **				
0-5 years old	9,754 (35.4)	9,880 (35.4)	10,130 (35.1)	9,261 (35.4)
6-10 years old	8,259 (27.5)	8,350 (27.4)	8,586 (27.4)	7,783 (27.2)
11-17 years old	10,341 (37.1)	10,511 (37.1)	10,927 (37.5)	9,950 (37.4)
Race/Ethnicity**				
Hispanic	10,636 (22.0)	10,764 (22.1)	11,267 (22.4)	9,922 (21.5)
NH White	8,630 (53.1)	8,815 (53.3)	8,930 (52.8)	8,460 (54.0)
NH Black	5,809 (13.5)	5,835 (13.3)	6,050 (13.5)	5,493 (13.3)
NH Asian	1,533 (4.7)	1,550 (4.7)	1,599 (4.7)	1,442 (4.6)
NH Other/Multi-race	1,746 (6.7)	1,777 (6.6)	1,797 (6.6)	1,677 (6.7)
Nativity Status				
Not born in US	914 (2.7)	935 (2.7)	973 (2.8)	843 (2.7)
Born in US	24,373 (97.3)	24,729 (97.3)	25,435 (97.2)	23,248 (97.3)
US Census Region				
Northeast	4,511 (18.3)	4,601 (18.5)	4,731 (18.4)	4,280 (18.3)
Midwest	5,439 (21.5)	5,492 (21.4)	5,664 (21.5)	5,198 (21.7)
South	11,005 (38.0)	11,109 (37.8)	11,439 (37.8)	10,515 (37.9)
West	7,399 (22.2)	7,539 (22.3)	7,809 (22.4)	7,001 (22.1)
Language**				
English	22,455 (90.4)	22,795 (90.5)	23,369 (90.2)	21,588 (90.8)
Spanish	5,777 (9.6)	5,814 (9.5)	6,140 (9.8)	5,287 (9.2)
Health Insurance**				
Any Private	12,158 (61.5)	12,349 (61.7)	12,656 (61.6)	11,712 (62.1)
Public Only	15,501 (36.3)	15,688 (36.2)	16,256 (36.3)	14,633 (35.8)
Uninsured	695 (2.1)	704 (2.1)	731 (2.1)	649 (2.1)
Usual Source of Health Care**				
No	1,383 (4.1)	1,418 (4.1)	1,477 (4.2)	1,351 (4.2)
Yes	26,745 (95.9)	27,088 (95.9)	27,921 (95.8)	25,430 (95.8)
Family Income (%FPL)**				
Poor/Negative (<100%)	9,273 (18.3)	9,353 (18.2)	9,722 (18.3)	8,692 (18.0)
Near Poor (100%-125%)	2,002 (5.2)	2,034 (5.2)	2,112 (5.3)	1,880 (5.1)
Low Income (125%-<200%)	4,781 (14.5)	4,854 (14.5)	5,008 (14.5)	4,557 (14.4)
Middle Income (200%-<400%)	6,824 (29.3)	6,944 (29.3)	7,108 (29.3)	6,592 (30.0)
High Income (≥400%)	5,474 (32.7)	5,556 (32.8)	5,693 (32.7)	5,273 (32.9)
Perceived Health Status**				
Excellent	15,452 (58.3)	15,608 (58.0)	15,981 (57.6)	14,833 (58.8)
Very Good	7,461 (26.9)	7,575 (27.0)	7,855 (27.1)	7,063 (26.5)
Good/Fair/Poor	5,343 (14.9)	5,548 (15.0)	5,797 (15.3)	5,090 (14.7)
Mental Health Status**				

Excellent	16,626 (61.7)	16,788 (61.3)	17,249 (61.1)	15,923 (62.1)
Very Good	6,534 (23.9)	6,663 (24.3)	6,870 (24.1)	6,240 (24.0)
Good/Fair/Poor	5,171 (14.4)	5,265 (14.4)	5,499 (14.7)	4,811 (14.0)
Special Health Care Needs**				
No	22,245 (77.6)	22,496 (77.6)	23,189 (77.5)	21,115 (77.5)
Yes	6,109 (22.4)	6,245 (22.4)	6,454 (22.5)	5,879 (22.5)

Abbreviations: FPL=federal poverty level; NH=non-Hispanic; PFCC=patient- and family-centered care.

**Weighted chi-square, $p=.0460$ when comparing child health conditions and parent's perceptions of whether or not their provider always explained things.*

***Weighted chi-square, $p<.05$ when comparing child age, race/ethnicity, census region, language, health insurance, usual source of care, family income, perceived health status, mental health status, and special health care needs with parents' perceptions of all qualities of PFCC (listened carefully, explained things, showed respect, spent enough time).*

Table 2: Crude and multivariable* logistic regression results for each quality of PFCC, Medical Expenditure Panel Survey 2013-2017.

	Listened carefully		Explained things		Showed respect		Spent enough time	
	Crude <i>OR (95% CI)</i>	Adjusted* <i>OR (95% CI)</i>	Crude <i>OR (95% CI)</i>	Adjusted* <i>OR (95% CI)</i>	Crude <i>OR (95% CI)</i>	Adjusted* <i>OR (95% CI)</i>	Crude <i>OR (95% CI)</i>	Adjusted* <i>OR (95% CI)</i>
Development or chronic health conditions								
No (ref)	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Yes	0.91 (0.81, 1.02)	0.89 (0.79, 1.01)	0.90 (0.80, 1.00)	0.88 (0.79, 0.99)	0.91 (0.82, 1.01)	0.91 (0.81, 1.02)	0.91 (0.82, 1.01)	0.91 (0.82, 1.01)

Abbreviations: CI=confidence interval; OR=odds ratio; PFCC=patient- and family-centered care.

**Multivariable models adjusted for child age, child sex, child race/ethnicity, family income, language, child usual source of care, and child health insurance*