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Exploring predictors in the receipt of patient/family-centered care

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Exploring predictors in the receipt of patient/family-centered care

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by

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Dedication

This dissertation is dedicated to all the medical warriors out there who are battling with chronic illness, to their caregivers, to all the amazing health care providers who are helping to support patients, to researchers who are working hard to find treatments, cures, and improve patient quality of life, quality of care, and the field of medicine. It is also dedicated to my amazing husband Roberto. Without him this dissertation would not have been written. A warm thank you to him for all the support, love, and workload that he took on to help me make this happen. Words can not express my gratitude to him.

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Abstract

This linking document provides an overview of two studies that explore the predictors of patient/family-centered care. It discusses the problem of the receipt of PFCC, specific populations that experience disparities in the receipt of PFCC, and a theoretical framework for the receipt of PFCC. It then provides an overview of the two studies and the survey that they utilize; The National Survey of Children's Health 2018-2019. Finally, it discusses the significance of the two studies.

Linking Document

This dissertation presented a line of research that explored patient/family-centered care (PFCC) for children and their families and was presented in a two-study format. Study two built upon the work of study one. This linking document highlighted each study. A brief statement and rationale of the problem were presented as an introduction to provide context.

Statement of the problem

The delivery of high-quality health care is a priority for health systems, states, federal funders, and policymakers. It can signal the success of a health system, health initiative, or program. High-quality health care is defined as care that is effective, safe, equitable, timely, and people-centered (Geneva: World Health Organization (WHO), 2018; Institute of Medicine & Committee on Quality of Health Care in America, 2001). Higher levels of quality of care have been associated with improved patient welfare which includes health outcomes, patient safety, patient satisfaction, and a focus on patient concerns and values (Committee on Hospital Care, 2003; Busse et al., 2019; Geneva: World Health Organization (WHO), 2018). Conversely, lower levels of quality of care are associated with poorer health outcomes which can impact a patient's quality of life, ability to work, interpersonal relationships, and strain support systems (Antonisse & Garfield, 2018; Hughes et al., 2018; Megari, 2013).

Understanding why people receive the quality of care that they do is no easy task. There are complex interactions between patients/families, providers, and system-level factors that influence the quality of care that a patient/family receives (Britton et al. 2016). While understanding the mechanism for care delivery is challenging, we do know that not everyone receives the same quality of care (Azuine et al., 2015; Feagin & Bennefield, 2014; Guerrero et al. 2010). People of color (POC), children with special health care needs (CSHCN), and children with less than excellent health

(CLEH) are less likely to receive high-quality care when compared to those who identify as white, not having a special need, or in excellent health (Brannon et al., 2021; Martin et al., 2013; Montes & Halterman, 2011). People of color are also more likely to experience poorer health outcomes with increased risks of morbidity and mortality (Flores & the Committee on Pediatric Research, 2010). We also know that where someone lives geographically is associated with the quality of care they receive (Azuine et al., 2015; Zickafoose et al., 2012) and should be considered when analyzing health data. For example, there is a higher proportion of children receiving high-quality care living in VT, WV, ND, NH, and NE than those living in NM, DC, NV, CA, or TX (Zickafoose et al., 2012).

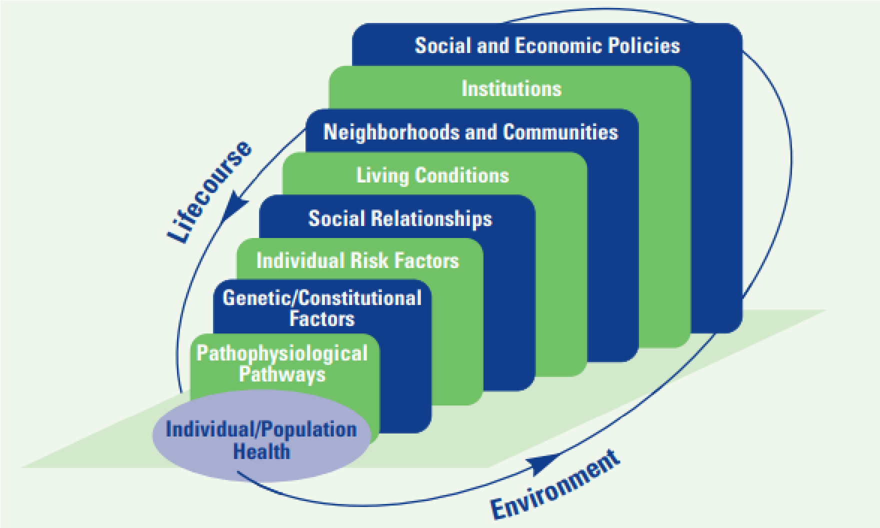
It is important that we measure the quality of care received and understand what factors are associated with increased odds of receiving high-quality care. It is also important to focus on systemic factors that can be changed to increase the quality of care received and increase protective factors for POC and other populations who are less likely to have positive health outcomes due to systemic issues and institutionalized structures. One healthcare delivery method that has been shown to decrease racial/ethnic health disparities and increase positive health outcomes for everyone is patient/family-centered care (PFCC) (Gance-Cleveland, 2006; Goldfarb et al., 2017; Lilly, et al., 2000). Patient/family-centered care is a collaborative and strengths-based approach to delivering healthcare to patients. PFCC is multifaceted and includes the planning, delivery, and evaluation of patient care (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012). This type of delivery method can be measured using patient-reported survey data and then used as a tool to systematically research the person-centeredness of the quality of care received by patients across communities, contexts, and regions.

The Rationale for Study of the Problem

This dissertation was designed to help build a clearer understanding of the odds of receiving PFCC by children/families, to what extent receipt of PFCC is associated with state of residence, and which predictors are either 1) protective factors for, or 2) barriers to providing PFCC, especially to the three populations of interest (POC, CSHCN, CLEH). To understand PFCC more deeply, I used an ecological perspective that takes a multilevel approach to address epidemiological concerns of health problems and health promotion. As seen in Figure 1, this approach considers the interaction and interdependence across all levels that impact health problems and health promotion (National Cancer Institute, 2005). The interactions and interdependencies between these levels are complex and make it difficult to study health outcomes, protective factors, and disparities. To conceptualize this complexity, I used the Ecological Perspective of the Levels of Influence for Health Behavior (Table 1) (National Cancer Institute, 2005).

Figure 1

A Multilevel Approach to Epidemiology

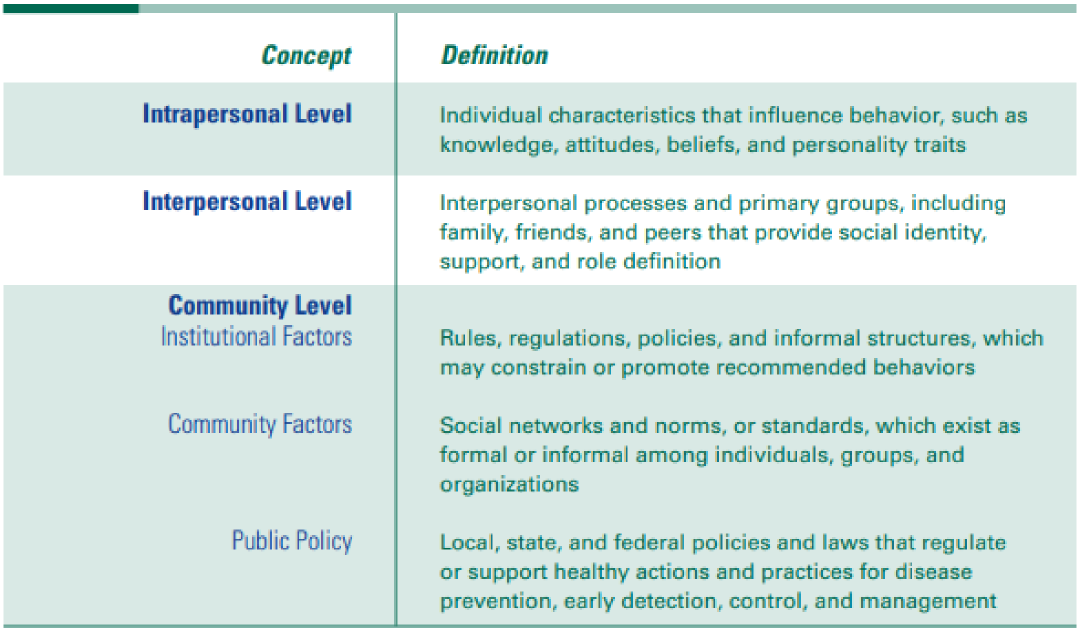


Source: Smedley BD, Syme SL (eds.), Institute of Medicine. Promoting Health: Strategies from Social and Behavioral Research. Washington, D.C.; National Academies Press, 2000.

Note. Figure 1 has been used with permission from the National Cancer Institute.

Table 1

An Ecological Perspective: Levels of Influence



Concept	Definition
Intrapersonal Level	Individual characteristics that influence behavior, such as knowledge, attitudes, beliefs, and personality traits
Interpersonal Level	Interpersonal processes and primary groups, including family, friends, and peers that provide social identity, support, and role definition
Community Level	
Institutional Factors	Rules, regulations, policies, and informal structures, which may constrain or promote recommended behaviors
Community Factors	Social networks and norms, or standards, which exist as formal or informal among individuals, groups, and organizations
Public Policy	Local, state, and federal policies and laws that regulate or support healthy actions and practices for disease prevention, early detection, control, and management

Note. Table 1 has been used with permission from the National Cancer Institute.

Table 1 outlines that there are intrapersonal, interpersonal, and community-level influences that impact health behavior, which in turn can change health outcomes and disparities of an individual/population. First, at the community level, institutional factors (rules, policies, regulations, informal structures, etc.) are important because they dictate how long a provider may spend with a patient, require providers to attend cultural competency training, promote equitable care, and many other important factors (Kuo et al., 2011; McDonough et al., 2004). These factors can lead to better outcomes for an individual and for improving a health system culture that supports high-quality care delivery (Hlavac et al., 2018; Kuo et al., 2011; Majumdar et al., 2004). Alternatively, they could support racism, discrimination, or focus on revenue over the quality of care delivered. Secondly, community factors (social networks, formal and informal standards, and norms for groups and organizations) can unconsciously signal to providers and patients how to interact with one another based on race/ethnicity, physical ability, age, power-distance due to role definitions, and many other factors (Carde, 2019; Paternotte et al., 2015). Lastly, public policy (local, state, federal policies, and laws), which can vary geographically, can impact health by supporting or hindering access, coverage, funding of health programs, regulations, etc. (National Conference of State Legislatures, 2014).

Most studies of the quality of care received do not consider where the child/family lives; however, it is documented that this is an important determinant of health (Montes & Halterman, 2011; Toomey et al., 2013). Those that have considered geography, rely on a reference state to compare all other states to, which can be an important baseline but limits the usefulness of the findings by not allowing for a comprehensive comparison. The current studies conceptualize children/families within the context of the state in which they live. They consider and control for demographic characteristics, focus on the geographical location both in a logistic regression and a multilevel model, and consider how various levels of influence might impact their health outcomes and the quality of care that they receive.

The current studies are needed to improve upon the previous methodology in the study of PFCC or explore new ways to examine it. These studies do so in three ways. First, the current studies provide insight into the quality of care received for each state using more recent data than previous studies for comparison. Secondly, in study 2, modeling that allowed for state-to-state comparison without the need for a reference state was utilized. Lastly, no other study has explored PFCC using multilevel modeling to account for possible contextual factors with a focus on CSHCN and health status predictors by state. Understanding what predictors are associated with PFCC with a consideration for state could help provide direction to state policymakers, funders, and health systems for improving the quality of care delivered to children/families in their state. This includes creating a clearer understanding of PFFC for specific populations and understanding between vs within-state differences in the receipt of PFCC. Lastly, a mapping data visualization was used to understand differences between states in the receipt of PFCC by CSHCN status and health status. This allowed the reader to easily compare results among states.

Data Source

The Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB) sponsors the NSCH, which is conducted by the United States Census Bureau. The NSCH is a nationally representative survey of non-institutionalized children ages zero to seventeen (Data Resource Center for Child and Adolescent Health, 2020). Surveys are conducted annually by mail or via the web and collect data about multiple aspects of children's health and well-being. This survey considers the intersectionality's of children's health by including questions about physical and mental health, access to health care, quality of care, information about the child's family, neighborhood, school, and social context (Child and Adolescent Health Measurement Initiative, 2019). The results of this survey provide estimates for the Title V Maternal and Child Health Services Block Grant, national outcome and performance measures, and data that is used by state health departments in their Title V needs assessment which is required to be submitted every five years (Health Resources and Services Administration, 2020). It is important to note that in 2012, the American Academy of Pediatrics published an article suggesting that the term patient/family-centered care (PFCC) be used in place of family-centered care (FCC). This change was suggested to highlight the importance of including both the family and the patient in a supportive and collaborative way. Although the NSCH has not adopted this new language, these studies will use the term PFCC instead of FCC.

To establish reliability and validity for the NSCH, many items were incorporated that originated from validated surveys that are commonly used in a clinical setting (Data Resource Center for Child and Adolescent Health, 2011). Other items were developed and validated for use with the population in which they were intended to measure (Data Resource Center for Child and Adolescent Health, 2011). The National Quality Forum endorsed the NSCH as a national and state-level population-based measure in 2006 (Data Resource Center for Child and Adolescent Health, 2011; U.S. Census Bureau, 2019). To achieve this, the NSCH had to meet criteria in four different areas including the importance and need for the measure, scientific acceptability of the measurement properties, usability of the measure in non-tested settings, and feasibility of successful replication (Data Resource Center for Child and Adolescent Health, 2011). An in-depth analysis of nonresponse bias is conducted annually and any adjustments to response weights are added if needed to control for complex survey design (United States Census, 2020). Additionally, many other studies of PFCC have used this survey with the pediatric age population (Azuine et al., 2015; Kan et al., 2016; Toomey et al., 2013; Weller et al., 2019; Zickafoose et al., 2012).

Study One Overview

Study One

Study one focused on the association between predictors and the receipt of PFCC, with a special focus on child race/ethnicity, health status, and CSHCN status. In order for states, grantors, and training programs to focus their efforts on improving the quality of care received, it is important to understand what predictors are most highly associated with high-quality care. To gain these insights, I investigated the following research aim:

RA1. Identify predictors associated with the receipt of PFCC among U.S. children/families.

I used the NSCH to conduct a secondary data analysis and employed hierarchical model building using ordinal logistic regression to obtain AORs and 95% confidence intervals (CIs). Logistic regressions were models were run for each of the dichotomous component models. A check of assumptions for regression followed all final models. Results will allow state policymakers, funders, and health systems to examine protective factors and challenges to the receipt of PFCC.

Study Two

Study two focused on the importance of examining results by state while controlling for predictors. It made the case that due to state variability in health systems, culture, health priorities, policies, politics, and insurance/Medicaid access and coverage, it is important to consider and explore the role of the state in the quality of care received by children/families (Azuine et al., 2015; Bethell et al., 2011; National Conference of State Legislatures, 2014; Singh, et al., 2009). Special attention was paid to the quality of care received by CSHCN status and health status by state. I explored the following research aims:

RA1. Examine differences across states in the amount of PFCC received that is associated with state differences

RA2. Identify states with the highest and lowest amount of PFCC received among U.S. children/families

RA3. Identify states with the highest and lowest amount of PFCC received among U.S. children/families by health status and CSHCN status

Research aim one was examined by utilizing a multilevel model that included many child-level predictors and included state as a level-two predictor. To address RA2 and RA3, a linear regression that controlled for variance between states and produced an additional output for receiving PFCC was used. This output indicated the average number of components a child/family living in that state received. This method did not require the use of a reference group like in traditional regression models. A heat map of the United States was created to show the approximate relative variation in the receipt of PFCC across the country for the total population, CHSCN, and CLEH. The discussion focused on the quality of care variations by state.

Significance of Studies

Patient/family-centered care has many stakeholders with whom the results of these studies may provide valuable insights. First, health care providers can gain awareness of which aspects of PFCC are less likely to be provided and to whom. Providers can use the information about individual components as a starting point for reflection about what components of PFCC they might need additional training in to increase their ability to provide PFCC. Second, training programs can use the results to tailor their programs to focus on the least delivered components of PFCC and on how to better support populations less likely to receive high-quality care to increase their trainee's ability to provide PFCC. Third, funders, policymakers, and states can identify states with the greatest need for support and funding for the quality of care received by children/families. Results can guide states to identify policy changes and initiatives needed to support PFCC in their state, including requirements for health systems. Top-performing states can be identified and studied. These states can collaborate with others to help provide guidance where appropriate.

Definition of Terms/ Abbreviations

1. **AOR**: Adjusted Odds Ratio
2. **CAHMI**: The Child and Adolescent Health Measurement Initiative
3. **CDC:** Center for Disease Control and Prevention
4. **CSHCN:** Children with Special Health Care Needs
    a. Children who require more care for their physical, developmental, behavioral, or emotional differences than their typically developing peers. A special healthcare need can include physical, intellectual, and developmental disabilities, as well as long-standing medical conditions. (CDC, 2021)
5. **FPL**: Federal Poverty Level
6. **HRSA:** Health Resources & Services Administration
7. **MCHB**: Maternal Child Health Bureau
8. **MLM**: Multilevel Model
9. **NSHC:** National Survey of Children's Health
10. **PFCC:** Patient/Family-centered care
    a. An approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care by placing an emphasis on collaborating with people of all ages, at all levels of care, and in all health care settings. In Inpatient- and family-centered care, patients and families define their "family" and determine how they will participate in care and decision-making. A key goal is to promote the health and well-being of individuals and families and to maintain their control. (Institute For Patient and Family-Centered Care, 2021)
11. **POC**: People of color
    a. "A person whose skin pigmentation is other than and especially darker than what is considered characteristic of people typically defined as white." (Merriam-Webster, 2021)
12. **WHO**: World Health Organization

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Exploring Predictors in the Receipt of Patient/Family-Centered Care

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Abstract

OBJECTIVES: The research aim of this study was to identify predictors associated with the receipt of PFCC among U.S. children/families

METHODS: Caregivers of 38,803 non-institutionalized children, aged 0 to 17 years, were surveyed by the National Survey of Children's Health (NSCH) 2018–20019. Patient/family-centered care (PFCC) was measured using five components of health care delivery that were answered on a 4-point Likert scale. Logistic regression models were analyzed for the overall receipt of PFCC and each component of PFCC, with survey weighting added to adjust for complex sampling design.

RESULTS: Many predictors were associated with the receipt of PFCC. Those with lower odds of receiving higher levels of PFCC included children with special health care needs (CSHCN) or children with less than excellent health (CLEH), the uninsured, those whose usual place of sick care was the hospital outpatient department, clinic or health center, or retail store clinic or minute clinic, those without a personal doctor or nurse, those in households whose primary language in the home is non-English, those who do not agree that they live in safe neighborhoods or attend safe schools, those below the 400% FPL, those with mother's who have a physical or mental health concern, and those with parents who were born outside of the country. The five states with the lowest receipt of higher levels of PFCC were Wyoming, Alabama, Oklahoma, Mississippi, and Virginia. Conversely, the five states with the highest levels of PFCC were Minnesota, Connecticut, New York, Ohio, and Colorado. Results by component were mostly consistent with the "final overall" model but somewhat varied.

CONCLUSION: Many predictors were significantly associated with PFCC and require further exploration. Future research should utilize a mixed-methods design to better understand the quantitative results of the NSCH as well as the barriers and mechanisms for disparities that are present at the provider and systems level to deliver PFCC.

KEYWORDS: patient/family-centered care; PFCC components; NSCH 2018-2019; health care quality; National Survey of Children’s Health; United States;

Exploring Predictors in the Receipt of Patient/Family-Centered Care

Health disparities are a primary concern in public health (U.S. Department of Health and Human Services (HHS), 2020; Office of Disease Prevention and Health Promotion (ODPHP), 2020; Sanchez et al., 2014). People of color (POC), those with special health care needs, and other populations who are under-resourced or societally disempowered are less likely to receive high-quality care and more likely to experience worse health outcomes than those in more resourced and empowered populations; including increased risk of morbidity and mortality (Braveman et al., 2011; Britton et al, 2016; Feagin & Beenefield, 2014; Flores & the Committee on Pediatric Research, 2010; Gance-Cleveland, 2006; Ragavan et al., 2020; Smalley et al., 2013). Recent research has shifted from learning if there are health disparities for those who are under-resourced or disempowered, to understanding the inequities that act as a mechanism behind those disparities (Magnusson & Mistry, 2017). Examples of these inequities include racism, lack of access to quality education, ableism, income/wage gaps, inadequate housing, unsafe work/home environments, discrimination, etc. (U.S. Department of Health and Human Services, 2020; Mendez et al., 2014). As stated by the World Health Organization (WHO, 2018), these inequities are unjust and could be improved with health and governmental policies.

Eliminating health disparities and achieving health equity is a goal in many state and federal programs and initiatives (HHS, 2020; ODPHP, 2020; Braveman et al., 2011). Understanding what policy changes need to be made to improve health equity is challenging due to the complex interactions between patients, providers, health systems, and other systemic and institutional factors that may contribute to inequity (Britton et al. 2016). These complex and multilayered interactions require that researchers continue moving from studying the disparities themselves to understanding the *mechanisms* that drive the inequities in health care quality research (Magnusson & Mistry, 2017).

This study focuses on a few factors that may contribute to disparities and inequities; mainly, health status and conceptually considering the child/family within the context of where they live and the provider and patient interaction. For the purposes of this study, patient-provider interaction is measured using patient- and family-centered care (PFCC). PFCC is an approach to providing care that is utilized by healthcare providers to deliver high-quality and equitable care to patients (Franck & O'Brien, 2019; Hsu et al., 2019). This approach can reduce health disparities for under-resourced populations and improve health outcomes for all patients (Gance-Cleveland, 2006; Goldfarb et al., 2017; Lilly, et al., 2000).

This study had one research aim. Utilizing the 2018-2019 National Survey of Children's Health (NSCH), a series of multiple logistic regression models are used to identify predictors associated with the receipt of PFCC among U.S. children/families. This analysis helped to identify which components of PFCC have the greatest disparity or protective factors by subpopulation. Results may be used to build evidence for programs and policies to focus on the implementation of PFCC in practice and training, with a focus on the aspects of PFCC that are the least likely to be received.

Methods

Data Source and Sample

The National Survey of Children's Health (NSCH) is a nationally representative survey of non-institutionalized children ages 0-17 that is conducted annually to measure the health and wellbeing of children in the United States. Addresses from households that are more likely to have children are selected to participate from all fifty states and the District of Columbia (DC). Participants are initially contacted via mail to complete the screening form online or on a paper-based form. Screening forms ask basic demographic information about each of the four youngest children in the home and questions about special health care needs that the children may have (Data Resource Center for Child and Adolescent Health, 2018). A child is then randomly chosen from the household to be the child of interest and a caregiver living in the household self-administers the topical survey. The NSCH utilizes oversampling for children under the age of five and children with special health care needs. The NSCH is funded and directed by the Maternal and Child Health Bureau (MCHB) of the Health and Resource Services Association (HRSA). Results from the NSCH are used to examine national and state performance measures of child and family health. The Child and Adolescent Health Measurement Initiative (CAHMI, 2022) provides a public use file of the NSCH dataset that includes calculated variables. The 2018-2019 NSCH dataset included 59,963 responses with an overall response rate of 43.1% in 2018 and 42.4% in 2019. An average of 1,176 survey responses were collected for each state, with a range of 1,021 to 1,420 responses (Data Resource Center for Child and Adolescent Health, 2020). The NSCH has developed and included survey weights to help researchers control for complex survey design. See the statistical analysis section of this study to learn how they were used with final models in this study.

Outcome and Exclusions

The receipt of PFCC was created as a composite variable from five 4-point Likert-scale items ranging from “never” to “always”. These five items asked how often the provider spent enough time with the family, listened carefully to the family, was sensitive to the values and customs of the family, provided specific information to the family, and made the family feel like a partner in their care. To look at each component individually, if a respondent selected “usually” or “always” to a specific component, then they received that component of PFCC. The sum of the components received for each respondent was stored as the composite variable for PFCC ranging from 0-5. The initial sample size was 59,963. The final sample included 38,803 responses after exclusion criteria.

Exclusions included children who did not have an appointment with a healthcare provider in the last twelve months (*N* = 9,486), whose caregivers did not respond to all five PFCC items (*N* = 1,399), or had any missing data for the included predictors (*N* = 10,275).

Individual Characteristics

Individual characteristics were used as control variables in the ordered logistic regression. Individual child-level demographic characteristics included the sex of the child (female, male), age of the child in years (0-17), child race/ethnicity (Hispanic, White, Black Asian, American Indian or Alaska Native, Native Hawaiian and Other Pacific Island, Multi-Race, Other), child nativity (born in the United States, born outside of the United States), and insurance type (public health insurance only, private health insurance only, public and private insurance, currently uninsured). Individual child-level need characteristics included special health care status (SHCN, non-SHCN), and child health status (fair or poor, good, very good or excellent). Individual child-level care characteristics included personal doctor or nurse (PDN) (have at least one PDN, do not have a personal doctor or nurse), and place for usual sick care (doctor's office, hospital emergency room, hospital outpatient department, clinic or health center, retail store clinic or ‘minute clinic’, school (nurse's office, athletic trainer's office), some other place).

Individual child-level household characteristics included household language (English, non-English), neighborhood safety (definitely agree, somewhat agree, somewhat/definitely disagree), school safety (definitely agree, somewhat agree, somewhat or definitely disagree), state of residence (50 states and the District of Columbia), family structure (two parents currently married, two parents not currently married, single parent, grandparent, other family types), and federal poverty level (FPL) (0-99%, 100-199%, 200-399%, 400% or above).

Individual child-level caregiver characteristics included caregiver sex (female, male), mother health status (physical & mental health both excellent/very good, one or both of physical & mental health are not excellent/very good, No mother reported in the household), father health status (physical & mental health both excellent/very good, one or both of physical & mental health are not excellent/very good, no father reported in the household), the highest level of education among reported adults in the household (less than high school, high school or GED, some college or technical school, college degree or higher).

Statistical Analyses

All descriptive statistics and analyses were conducted using Stata 14 (StataCorp., 2015). The ologit function was used to analyze the ordered overall receipt of PFCC. Ordered logistic regression was used to identify child characteristics associated with the receipt of PFCC (Liu, 2015). This differs from a traditional logistic regression, which has a dichotomous outcome. For the overall receipt of PFCC, if a dichotomous outcome was used, an arbitrary number of components received would have had to be chosen. In 2013, the NSCH changed their binary composite variable for receipt of PFCC to only require one component to have received PFCC (Data Resource Center for Child and Adolescent Health, 2021). Previously they required all components to have been received to consider the child/family to have received PFCC (Data Resource Center for Child and Adolescent Health, 2013). Using an ordered outcome allows for a more sensitive measure that can examine a respondent's odds of receiving higher levels of care rather than a binary outcome (e.g., moving from receiving two components of PFCC to receiving three components).

Dichotomous component models were analyzed using the logit function. These logistic regression models were more practical for component outcomes because the interest was in the receipt of each variable individually, not the degree of care or of higher levels of that component being received (Hilbe, 2009; Hosmer et al., 2013). The Likert scale used for the component questions only included four options, which would have been difficult to analyze other than dichotomously. To more accurately adjust standard errors for state memberships in both the ordered and dichotomous logistic regression models, cluster robust standard errors were used. To ensure that estimates are representative of the larger population and control for complex sampling design, survey weights, provided by the NSCH, were applied. Multicollinearity was assessed using the variance inflation factor with a tolerance threshold below 0.2 to ensure multicollinearity was not present in the final models.

Models

The analytic approach comprised eleven models including a null model, 5 hierarchical models for the ordinal receipt of PFCC (Table 1), and one model for each binary component outcome (Table 2). Each hierarchical model included all variables from the previous model and added a new category of variables for the ordinal receipt of PFCC. This assisted with assessing model fit. The five component models included all predictors and a binary outcome for each of the components (Table 2). All model outputs included AORs, CI, and p-values for each variable.

Table 1

Hierarchical model building overall model

Model No.	Characteristics included
0	Null model with no characteristics included
1	Child-level demographic characteristics
2	Child-level need characteristics
3	Child-level care characteristics
4	Child-level household characteristics
5	Child-level caregiver characteristics
6	Child-level race/ethnicity added. Final overall model.

Table 2

Individual PFCC component models

Model	Characteristics included
Listened Carefully Model	All characteristics from overall model. Listened carefully as outcome.
Spent Enough Time Model	All characteristics from overall model. Spent enough time as outcome.
Provided Specific Information Model	All characteristics from overall model. Provided specific information as outcome.
Showed Culturally Sensitive Model	All characteristics from overall model. Showed cultural sensitivity as outcome.
Felt like a Partner Model	All characteristics from overall model. Felt like a partner as outcome.

Results

Table 3 displays the demographic and health characteristics of the child and family, which are nationally representative of non-institutionalized children in the United States (U.S.) ages 0-17. Characteristics are stratified by the number of components of PFCC that they received. The population was predominantly female, born in the US, 12-17 years old, White, without a special health care need, in excellent or very good health, had private health insurance only, received care primarily at a doctor's office when sick, had at least one personal nurse or doctor, spoke English in the home, definitely agreed that their school and neighborhood were safe, lived in two-parent married households, with both mother and father in excellent health, and had a federal poverty level of 400% or above. After exclusion criteria, of the 40,349 survey responses in 2018-2019, 38,485 received four or five components of PFCC (95%).

Model Fit

The goodness of fit was explained by the Pseudo R-squared statistic. The R-squared statistic can vary between 0 and 1, and is typically interpreted as a percentage. The Pseudo R-squared is similar to the R-squared statistic in linear regression applied to generalized linear models. Zero percent means that the model did not explain any variation in the receipt of PFCC. One hundred percent would mean that all of the variation in the receipt of PFCC was explained by the model. The "final overall" model explained 7% of the variance in the receipt of PFCC when covariates were included. Component models were better explained than the "final overall" model (“spent enough time” model (10%), “felt like a partner” model (11%), “listened carefully” model (12%), “showed cultural sensitivity” model (12%), and “provided specific information” model (12%)).

Table 3

Characteristics of Children 0-17 in the Receipt of the Composite Patient/Family Centered Care Score, 2018-2019 National Survey of Children’s Health

Characteristic	Number of PFCC Components Received			
	0-1	2-3	4-5	Overall
Total	766	1098	38485	40349
Sex of Child				
Female	422 (55.1%)	600 (54.6%)	19967 (51.9%)	20989 (52.0%)
Male	344 (44.9%)	498 (45.4%)	18518 (48.1%)	19360 (48.0%)
Born in USA				
Born in US	749 (97.8%)	1066 (97.1%)	37405 (97.2%)	39220 (97.2%)
Born outside of US	13.0 (1.7%)	29.0 (2.6%)	964 (2.5%)	1006 (2.5%)
Missing	4.00 (0.5%)	3.00 (0.3%)	116 (0.3%)	123 (0.3%)

Table 3 Continued

Characteristics of Children 0-17 in the Receipt of the Composite Patient/Family Centered Care Score, 2018-2019 National Survey of Children’s Health

Characteristic	Number of PFCC Components Received			
	0-1	2-3	4-5	Overall
Child Age				

0-5	183 (23.9%)	325 (29.6%)	11600 (30.1%)	12108 (30.0%)
6-11	290 (37.9%)	357 (32.5%)	11625 (30.2%)	12272 (30.4%)
12-17	293 (38.3%)	416 (37.9%)	15260 (39.7%)	15969 (39.6%)
Child Race/Ethnicity				
Hispanic	116 (15.1%)	146 (13.3%)	3671 (9.5%)	3933 (9.7%)
White, non-Hispanic	484 (63.2%)	745 (67.9%)	28523 (74.1%)	29752 (73.7%)
Black, non-Hispanic	58.0 (7.6%)	68.0 (6.2%)	1935 (5.0%)	2061 (5.1%)
Asian, non-Hispanic	32.0 (4.2%)	40.0 (3.6%)	1458 (3.8%)	1530 (3.8%)
American Indian or Alaska Native Non-Hispanic	11.0 (1.4%)	8.00 (0.7%)	164 (0.4%)	183 (0.5%)
Native Hawaiian and Other Pacific Islander Non-Hispanic	2.00 (0.3%)	2.00 (0.2%)	53.0 (0.1%)	57.0 (0.1%)
Multi-Race Non-Hispanic	63.0 (8.2%)	84.0 (7.7%)	2566 (6.7%)	2713 (6.7%)
Other Non-Hispanic	0 (0%)	5.00 (0.5%)	115 (0.3%)	120 (0.3%)
Special Health Care Status				
SHCN	330 (43.1%)	412 (37.5%)	9956 (25.9%)	10698 (26.5%)
Non-SHCN	436 (56.9%)	686 (62.5%)	28529 (74.1%)	29651 (73.5%)
Child Health Status				
Excellent or very good	582 (76.0%)	896 (81.6%)	35536 (92.3%)	37014 (91.7%)
Good	141 (18.4%)	161 (14.7%)	2407 (6.3%)	2709 (6.7%)
Fair or Poor	42.0 (5.5%)	40.0 (3.6%)	470 (1.2%)	552 (1.4%)
Missing	1.00 (0.1%)	1.00 (0.1%)	72.0 (0.2%)	74.0 (0.2%)
Insurance Type				
Public health insurance only	233 (30.4%)	269 (24.5%)	6465 (16.8%)	6967 (17.3%)
Private health insurance only	428 (55.9%)	689 (62.8%)	29431 (76.5%)	30548 (75.7%)
Public and private insurance	52.0 (6.8%)	68.0 (6.2%)	1316 (3.4%)	1436 (3.6%)
Currently uninsured	39.0 (5.1%)	58.0 (5.3%)	992 (2.6%)	1089 (2.7%)
Missing	14.0 (1.8%)	14.0 (1.3%)	281 (0.7%)	309 (0.8%)

Table 3 Continued

Characteristics of Children 0-17 in the Receipt of the Composite Patient/Family Centered Care Score, 2018-2019 National Survey of Children's Health

Characteristic	Number of PFCC Components Received			
	0-1	2-3	4-5	Overall
Place for Usual Sick Care				

Doctor's Office	600 (78.3%)	889 (81.0%)	33903 (88.1%)	35392 (87.7%)
Hospital Emergency Room	11.0 (1.4%)	18.0 (1.6%)	266 (0.7%)	295 (0.7%)
Hospital Outpatient Department	11.0 (1.4%)	9.00 (0.8%)	201 (0.5%)	221 (0.5%)
Clinic or Health Center	109 (14.2%)	144 (13.1%)	3455 (9.0%)	3708 (9.2%)
Retail Store Clinic or 'Minute Clinic'	14.0 (1.8%)	22.0 (2.0%)	382 (1.0%)	418 (1.0%)
School (Nurse's Office, Athletic Trainer's Office)	9.00 (1.2%)	4.00 (0.4%)	128 (0.3%)	141 (0.3%)
Some other place	12.0 (1.6%)	12.0 (1.1%)	150 (0.4%)	174 (0.4%)
Personal Nurse or Doctor				
Have at least one PDN	491 (64.1%)	799 (72.8%)	32372 (84.1%)	33662 (83.4%)
Do not have a personal doctor or nurse	274 (35.8%)	298 (27.1%)	6024 (15.7%)	6596 (16.3%)
Missing	1.00 (0.1%)	1.00 (0.1%)	89.0 (0.2%)	91.0 (0.2%)
Household Language				
English	717 (93.6%)	1021 (93.0%)	36852 (95.8%)	38590 (95.6%)
Non-English	49.0 (6.4%)	77.0 (7.0%)	1633 (4.2%)	1759 (4.4%)
School Safety				
Definitely agree	255 (33.3%)	375 (34.2%)	19191 (49.9%)	19821 (49.1%)
Somewhat agree	248 (32.4%)	322 (29.3%)	6884 (17.9%)	7454 (18.5%)
Somewhat or definitely disagree	70.0 (9.1%)	69.0 (6.3%)	587 (1.5%)	726 (1.8%)
Children age 0-5 years	183 (23.9%)	325 (29.6%)	11600 (30.1%)	12108 (30.0%)
Missing	10.0 (1.3%)	7.00 (0.6%)	223 (0.6%)	240 (0.6%)
Neighborhood Safety				
Definitely agree	348 (45.4%)	552 (50.3%)	27061 (70.3%)	27961 (69.3%)
Somewhat agree	327 (42.7%)	463 (42.2%)	10127 (26.3%)	10917 (27.1%)
Somewhat or definitely disagree	88.0 (11.5%)	78.0 (7.1%)	1110 (2.9%)	1276 (3.2%)
Missing	3.00 (0.4%)	5.00 (0.5%)	187 (0.5%)	195 (0.5%)

Table 3 Continued

Characteristics of Children 0-17 in the Receipt of the Composite Patient/Family Centered Care Score, 2018-2019 National Survey of Children's Health

Characteristic	Number of PFCC Components Received			
	0-1	2-3	4-5	Overall
Family Structure				

Two parents, currently married	427 (55.7%)	721 (65.7%)	28976 (75.3%)	30124 (74.7%)
Two parents, not currently married	65.0 (8.5%)	105 (9.6%)	2197 (5.7%)	2367 (5.9%)
Single parent (mother or father)	233 (30.4%)	238 (21.7%)	6138 (15.9%)	6609 (16.4%)
Grandparent Household	31.0 (4.0%)	19.0 (1.7%)	894 (2.3%)	944 (2.3%)
Other relation	9.00 (1.2%)	13.0 (1.2%)	264 (0.7%)	286 (0.7%)
Missing	1.00 (0.1%)	2.00 (0.2%)	16.0 (0.0%)	19.0 (0.0%)
Federal Poverty				
0-99% FPL	158 (20.6%)	136 (12.4%)	3037 (7.9%)	3331 (8.3%)
100%-199% FPL	162 (21.1%)	237 (21.6%)	5422 (14.1%)	5821 (14.4%)
200%-399% FPL	261 (34.1%)	384 (35.0%)	11986 (31.1%)	12631 (31.3%)
400% FPL or above	185 (24.2%)	341 (31.1%)	18040 (46.9%)	18566 (46.0%)
Sex of Adult				
Male	175 (22.8%)	294 (26.8%)	11596 (30.1%)	12065 (29.9%)
Female	591 (77.2%)	804 (73.2%)	26889 (69.9%)	28284 (70.1%)
Adult Education				
Less than high school	22.0 (2.9%)	30.0 (2.7%)	423 (1.1%)	475 (1.2%)
High school degree or GED	110 (14.4%)	138 (12.6%)	3585 (9.3%)	3833 (9.5%)
Some college or technical school	242 (31.6%)	302 (27.5%)	8103 (21.1%)	8647 (21.4%)
College degree or higher	392 (51.2%)	628 (57.2%)	26374 (68.5%)	27394 (67.9%)
Mother Health Status				
Physical & mental health BOTH excellent/very good	265 (34.6%)	480 (43.7%)	23617 (61.4%)	24362 (60.4%)
One or both of physical & mental health are NOT excellent/very good	414 (54.0%)	529 (48.2%)	12206 (31.7%)	13149 (32.6%)
No mother reported in the household	79.0 (10.3%)	77.0 (7.0%)	2435 (6.3%)	2591 (6.4%)
Missing	8.00 (1.0%)	12.0 (1.1%)	227 (0.6%)	247 (0.6%)

Table 3 Continued

Characteristics of Children 0-17 in the Receipt of the Composite Patient/Family Centered Care Score, 2018-2019 National Survey of Children's Health

Characteristic	Number of PFCC Components Received			
	0-1	2-3	4-5	Overall
Father Health Status				

Physical & mental health BOTH excellent/very good	245 (32.0%)	455 (41.4%)	21654 (56.3%)	22354 (55.4%)
One or both of physical & mental health are NOT excellent/very good	262 (34.2%)	387 (35.2%)	10070 (26.2%)	10719 (26.6%)
No father reported in the household	254 (33.2%)	244 (22.2%)	6558 (17.0%)	7056 (17.5%)
Missing	5.00 (0.7%)	12.0 (1.1%)	203 (0.5%)	220 (0.5%)
Parent Nativity				
Parent(s) born in US	607 (79.2%)	854 (77.8%)	31804 (82.6%)	33265 (82.4%)
Any parent born outside US	108 (14.1%)	194 (17.7%)	5373 (14.0%)	5675 (14.1%)
Other	40.0 (5.2%)	30.0 (2.7%)	1046 (2.7%)	1116 (2.8%)
Missing	11.0 (1.4%)	20.0 (1.8%)	262 (0.7%)	293 (0.7%)
State				
Alabama	22.0 (2.9%)	26.0 (2.4%)	742 (1.9%)	790 (2.0%)
Alaska	15.0 (2.0%)	14.0 (1.3%)	680 (1.8%)	709 (1.8%)
Arizona	14.0 (1.8%)	34.0 (3.1%)	712 (1.9%)	760 (1.9%)
Arkansas	20.0 (2.6%)	24.0 (2.2%)	889 (2.3%)	933 (2.3%)
California	18.0 (2.3%)	13.0 (1.2%)	656 (1.7%)	687 (1.7%)
Colorado	10.0 (1.3%)	17.0 (1.5%)	808 (2.1%)	835 (2.1%)
Connecticut	9.00 (1.2%)	15.0 (1.4%)	773 (2.0%)	797 (2.0%)
Delaware	14.0 (1.8%)	19.0 (1.7%)	738 (1.9%)	771 (1.9%)
District of Columbia	12.0 (1.6%)	25.0 (2.3%)	812 (2.1%)	849 (2.1%)
Florida	19.0 (2.5%)	18.0 (1.6%)	735 (1.9%)	772 (1.9%)
Georgia	20.0 (2.6%)	23.0 (2.1%)	802 (2.1%)	845 (2.1%)
Hawaii	6.00 (0.8%)	14.0 (1.3%)	536 (1.4%)	556 (1.4%)
Idaho	18.0 (2.3%)	31.0 (2.8%)	792 (2.1%)	841 (2.1%)
Illinois	16.0 (2.1%)	27.0 (2.5%)	711 (1.8%)	754 (1.9%)
Indiana	11.0 (1.4%)	23.0 (2.1%)	726 (1.9%)	760 (1.9%)
Iowa	11.0 (1.4%)	19.0 (1.7%)	791 (2.1%)	821 (2.0%)
Kansas	12.0 (1.6%)	24.0 (2.2%)	825 (2.1%)	861 (2.1%)
Kentucky	17.0 (2.2%)	20.0 (1.8%)	834 (2.2%)	871 (2.2%)
Louisiana	13.0 (1.7%)	23.0 (2.1%)	766 (2.0%)	802 (2.0%)
Maine	13.0 (1.7%)	19.0 (1.7%)	764 (2.0%)	796 (2.0%)
Maryland	10.0 (1.3%)	11.0 (1.0%)	736 (1.9%)	757 (1.9%)

Table 3 Continued

Characteristics of Children 0-17 in the Receipt of the Composite Patient/Family Centered Care Score, 2018-2019 National Survey of Children's Health

Characteristic	Number of PFCC Components Received			
	0-1	2-3	4-5	Overall
Massachusetts	16.0 (2.1%)	14.0 (1.3%)	814 (2.1%)	844 (2.1%)

Michigan	9.00 (1.2%)	26.0 (2.4%)	710 (1.8%)	745 (1.8%)
Minnesota	13.0 (1.7%)	16.0 (1.5%)	788 (2.0%)	817 (2.0%)
Mississippi	20.0 (2.6%)	26.0 (2.4%)	729 (1.9%)	775 (1.9%)
Missouri	17.0 (2.2%)	16.0 (1.5%)	811 (2.1%)	844 (2.1%)
Montana	21.0 (2.7%)	17.0 (1.5%)	746 (1.9%)	784 (1.9%)
Nebraska	14.0 (1.8%)	15.0 (1.4%)	739 (1.9%)	768 (1.9%)
Nevada	30.0 (3.9%)	27.0 (2.5%)	604 (1.6%)	661 (1.6%)
New Hampshire	9.00 (1.2%)	23.0 (2.1%)	890 (2.3%)	922 (2.3%)
New Jersey	12.0 (1.6%)	13.0 (1.2%)	743 (1.9%)	768 (1.9%)
New Mexico	23.0 (3.0%)	28.0 (2.6%)	720 (1.9%)	771 (1.9%)
New York	12.0 (1.6%)	18.0 (1.6%)	708 (1.8%)	738 (1.8%)
North Carolina	20.0 (2.6%)	16.0 (1.5%)	806 (2.1%)	842 (2.1%)
North Dakota	14.0 (1.8%)	23.0 (2.1%)	737 (1.9%)	774 (1.9%)
Ohio	6.00 (0.8%)	25.0 (2.3%)	770 (2.0%)	801 (2.0%)
Oklahoma	23.0 (3.0%)	26.0 (2.4%)	783 (2.0%)	832 (2.1%)
Oregon	16.0 (2.1%)	32.0 (2.9%)	770 (2.0%)	818 (2.0%)
Pennsylvania	11.0 (1.4%)	21.0 (1.9%)	802 (2.1%)	834 (2.1%)
Rhode Island	12.0 (1.6%)	27.0 (2.5%)	779 (2.0%)	818 (2.0%)
South Carolina	17.0 (2.2%)	32.0 (2.9%)	776 (2.0%)	825 (2.0%)
South Dakota	11.0 (1.4%)	22.0 (2.0%)	727 (1.9%)	760 (1.9%)
Tennessee	10.0 (1.3%)	17.0 (1.5%)	716 (1.9%)	743 (1.8%)
Texas	20.0 (2.6%)	21.0 (1.9%)	671 (1.7%)	712 (1.8%)
Utah	12.0 (1.6%)	24.0 (2.2%)	714 (1.9%)	750 (1.9%)
Vermont	12.0 (1.6%)	15.0 (1.4%)	822 (2.1%)	849 (2.1%)
Virginia	13.0 (1.7%)	36.0 (3.3%)	763 (2.0%)	812 (2.0%)
Washington	13.0 (1.7%)	19.0 (1.7%)	745 (1.9%)	777 (1.9%)
West Virginia	17.0 (2.2%)	24.0 (2.2%)	821 (2.1%)	862 (2.1%)
Wisconsin	16.0 (2.1%)	16.0 (1.5%)	713 (1.9%)	745 (1.8%)
Wyoming	27.0 (3.5%)	24.0 (2.2%)	740 (1.9%)	791 (2.0%)

Results by predictor

Study sample characteristics are described in Table 3 by the number of components received. Results by predictor for the "final overall" model and component models can be found in table 4. For reference, models one through five can be found in the Appendices. Below, results are summarized by key predictors. Estimates were adjusted for by all other predictors included in the model.

Special health care type

Children with special health care needs have 21% lower odds of receiving higher levels of PFCC than those without a special health care need in the "final overall" model, as shown in Table 4. When CSHCN were examined by component in the logistic regression models, results varied. Special health care status did not appear to be a significant predictor of “spending enough time” or “showing cultural sensitivity”, but was significant for “provided specific information” (45% lower odds), “listened carefully” (38% lower odds), and “feeling like a partner” (24% lower odds) when compared to children without a SHCN.

Child health status

Child health status in the "final overall" model showed that children with a good (34% lower) or fair/poor (48% lower) health status had lower odds of receiving higher levels of PFCC than those with excellent health. When child health status was examined by component in the logistic regression models, they were similar but varied slightly. Either good or fair/poor health status was significant in every model. In the “spent enough time” (28%, 33% lower) and “provided specific information” models (31%, 49% lower) both good and fair/poor health were statistically significant. In both the “showed cultural sensitivity” (41% lower) and “felt like a partner” (28% lower) models, only good health status was a significant predictor of receiving that component of PFCC. In the “listened carefully” model (40% lower), only fair/poor health status was a significant predictor of receiving those components of care. All model results showed that CLEH had lower odds of receiving PFCC than those with excellent health.

Table 4

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Parent Perceived Spent Enough Time AOR (95 % CI)	Parent Perceived Receipt of Specific Information AOR (95 % CI)	Parent Perceived Showed Cultural Sensitivity AOR (95 % CI)	Parent Perceived Listened Carefully AOR (95 % CI)	Parent Perceived Felt Like a Partner AOR (95 % CI)	Final Overall Model AOR (95 % CI)
Sex of Child						
Male	1.06 (0.87-1.28)	1.15 (0.92-1.44)	1.2 (0.93-1.55)	1.12 (0.93-1.35)	1.2 (0.95-1.51)	1.1 (0.94-1.3)
Female	Reference	Reference	Reference	Reference	Reference	Reference
Born in USA						
Born in US	Reference	Reference	Reference	Reference	Reference	Reference
Born outside of US	1.74 (1.12-2.71)	1.05 (0.6-1.83)	1.23 (0.69-2.19)	0.71 (0.43-1.17)	0.74 (0.43-1.29)	1.03 (0.71-1.5)
Child Age	1.13 (1-1.28)	1.18 (1.01-1.38)	1.28 (1.1-1.49)	1.28 (1.06-1.55)	1.1 (0.89-1.37)	1.12 (1.03-1.23)
Insurance Type						
Private health insurance only	Reference	Reference	Reference	Reference	Reference	Reference
Public health insurance only	0.97 (0.63-1.49)	1.01 (0.64-1.58)	0.86 (0.57-1.28)	1.05 (0.68-1.6)	1.15 (0.85-1.55)	1.04 (0.74-1.46)
Public and private insurance	0.92 (0.62-1.35)	0.64 (0.42-0.98)	0.72 (0.51-1.01)	0.98 (0.63-1.54)	0.7 (0.49-0.99)	0.86 (0.67-1.11)
Currently uninsured	1.03 (0.59-1.8)	0.51 (0.35-0.75)	0.68 (0.45-1.02)	0.79 (0.55-1.16)	0.78 (0.55-1.12)	0.76 (0.59-0.96)
Special Health Care Status						
Non-SHCN	Reference	Reference	Reference	Reference	Reference	Reference
SHCN	0.85 (0.72-1)	0.55 (0.43-0.7)	0.82 (0.66-1.04)	0.62 (0.49-0.78)	0.76 (0.59-0.97)	0.79 (0.7-0.89)
Child Health Status						
Excellent or very good	Reference	Reference	Reference	Reference	Reference	Reference
Good	0.72 (0.6-0.86)	0.69 (0.49-0.95)	0.59 (0.44-0.79)	0.83 (0.6-1.15)	0.72 (0.54-0.96)	0.68 (0.58-0.78)
Fair or Poor	0.67 (0.46-0.99)	0.49 (0.28-0.84)	0.62 (0.38-1.01)	0.6 (0.37-0.98)	0.6 (0.36-1.02)	0.51 (0.37-0.71)
Place for Usual Sick Care						
Doctor's Office	Reference	Reference	Reference	Reference	Reference	Reference

Table 4 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Parent Perceived Spent Enough Time AOR (95 % CI)	Parent Perceived Receipt of Specific Information AOR (95 % CI)	Parent Perceived Showed Cultural Sensitivity AOR (95 % CI)	Parent Perceived Listened Carefully AOR (95 % CI)	Parent Perceived Felt Like a Partner AOR (95 % CI)	Final Overall Model AOR (95 % CI)
Hospital Emergency Room	0.96 (0.51-1.81)	0.95 (0.5-1.8)	0.65 (0.36-1.19)	0.71 (0.32-1.57)	0.76 (0.34-1.67)	0.87 (0.5-1.5)
Hospital Outpatient Department	0.33 (0.14-0.78)	0.22 (0.07-0.62)	0.26 (0.09-0.73)	0.29 (0.08-1.06)	0.58 (0.21-1.59)	0.4 (0.16-0.97)
Clinic or Health Center	0.72 (0.5-1.05)	0.86 (0.58-1.26)	0.77 (0.57-1.03)	0.64 (0.46-0.9)	0.68 (0.55-0.83)	0.74 (0.56-0.97)
Retail Store Clinic or 'Minute Clinic'	0.56 (0.23-1.35)	0.31 (0.15-0.63)	0.31 (0.15-0.64)	0.25 (0.12-0.5)	0.34 (0.17-0.69)	0.41 (0.2-0.83)
School (Nurse's Office, Athletic Trainer's Office)	1.2 (0.38-3.73)	0.66 (0.19-2.35)	1.09 (0.25-4.84)	0.72 (0.23-2.22)	0.88 (0.23-3.32)	1.39 (0.5-3.87)
Some other place	0.76 (0.27-2.13)	0.54 (0.18-1.6)	0.56 (0.23-1.4)	0.29 (0.1-0.84)	0.55 (0.23-1.33)	0.75 (0.3-1.9)
Personal Nurse or Doctor						
Have at least one PDN	Reference	Reference	Reference	Reference	Reference	Reference
Do not have a personal doctor or nurse	0.43 (0.38-0.49)	0.43 (0.36-0.52)	0.45 (0.38-0.53)	0.44 (0.35-0.55)	0.4 (0.34-0.49)	0.47 (0.42-0.52)
Household Language						
English	Reference	Reference	Reference	Reference	Reference	Reference
Non-English	0.69 (0.48-0.99)	1.3 (0.77-2.2)	0.69 (0.38-1.25)	1.09 (0.54-2.19)	0.93 (0.6-1.42)	0.74 (0.57-0.96)
School Safety						
Definitely agree	Reference	Reference	Reference	Reference	Reference	Reference
Somewhat agree	0.53 (0.4-0.71)	0.59 (0.44-0.78)	0.49 (0.33-0.72)	0.68 (0.48-0.96)	0.49 (0.41-0.59)	0.54 (0.45-0.65)
Somewhat or definitely disagree	0.57 (0.39-0.82)	0.29 (0.18-0.49)	0.32 (0.19-0.54)	0.4 (0.26-0.61)	0.31 (0.19-0.5)	0.43 (0.31-0.59)
Children age 0-5 years	1.09 (0.87-1.38)	0.93 (0.67-1.27)	1.05 (0.68-1.61)	1.09 (0.81-1.48)	0.86 (0.55-1.34)	0.98 (0.82-1.18)
Neighborhood Safety						
Definitely agree	Reference	Reference	Reference	Reference	Reference	Reference
Somewhat agree	0.61 (0.47-0.77)	0.6 (0.42-0.87)	0.64 (0.54-0.75)	0.61 (0.45-0.82)	0.68 (0.59-0.8)	0.63 (0.53-0.75)

Table 4 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Parent Perceived Spent Enough Time AOR (95 % CI)	Parent Perceived Receipt of Specific Information AOR (95 % CI)	Parent Perceived Showed Cultural Sensitivity AOR (95 % CI)	Parent Perceived Listened Carefully AOR (95 % CI)	Parent Perceived Felt Like a Partner AOR (95 % CI)	Final Overall Model AOR (95 % CI)
Somewhat or definitely disagree	0.42 (0.29-0.59)	0.39 (0.3-0.51)	0.47 (0.34-0.65)	0.46 (0.35-0.62)	0.51 (0.38-0.68)	0.48 (0.37-0.63)
Family Structure						
Two parents, currently married	Reference	Reference	Reference	Reference	Reference	Reference
Two parents, not currently married	0.75 (0.52-1.07)	0.79 (0.52-1.22)	1.03 (0.7-1.53)	0.89 (0.62-1.28)	1.27 (0.78-2.06)	0.84 (0.63-1.12)
Single parent (mother or father)	0.55 (0.27-1.15)	0.65 (0.25-1.74)	0.52 (0.28-0.95)	0.46 (0.22-0.98)	0.51 (0.31-0.84)	0.57 (0.32-1.04)
Grandparent Household	0.93 (0.19-4.62)	0.97 (0.26-3.59)	1.1 (0.21-5.88)	0.88 (0.26-2.91)	1.1 (0.35-3.48)	1.25 (0.35-4.37)
Other relation	0.61 (0.13-3.01)	1.2 (0.42-3.42)	1.15 (0.22-5.93)	0.51 (0.26-1)	0.98 (0.48-1.97)	0.75 (0.2-2.81)
Federal Poverty						
0-99% FPL	0.91 (0.72-1.16)	0.68 (0.42-1.1)	0.59 (0.44-0.8)	0.57 (0.42-0.76)	0.6 (0.44-0.82)	0.74 (0.6-0.92)
100%-199% FPL	0.74 (0.59-0.93)	0.74 (0.49-1.13)	0.68 (0.42-1.1)	0.68 (0.5-0.92)	0.74 (0.46-1.18)	0.76 (0.59-0.96)
200%-399% FPL	0.75 (0.6-0.93)	0.68 (0.49-0.94)	0.73 (0.52-1.01)	0.8 (0.61-1.04)	0.78 (0.61-0.99)	0.76 (0.65-0.88)
400% FPL or above	Reference	Reference	Reference	Reference	Reference	Reference
State						
Alabama	0.71 (0.62-0.8)	0.62 (0.51-0.75)	0.76 (0.65-0.89)	0.74 (0.64-0.84)	0.84 (0.7-1)	0.74 (0.67-0.82)
Alaska	1.54 (1.37-1.72)	1.41 (1.11-1.79)	1.56 (1.26-1.93)	1.7 (1.35-2.13)	1.46 (1.23-1.75)	1.45 (1.31-1.6)
Arizona	0.8 (0.72-0.9)	1.35 (1.14-1.59)	1.16 (0.97-1.38)	1.91 (1.58-2.31)	1.6 (1.4-1.83)	0.87 (0.78-0.97)
Arkansas	1.03 (0.92-1.15)	0.79 (0.67-0.92)	1.21 (1.08-1.37)	1.07 (0.93-1.23)	1.05 (0.92-1.2)	1.01 (0.93-1.1)
California	1.07 (0.94-1.22)	1.25 (0.97-1.61)	1.47 (1.22-1.77)	2.35 (1.94-2.84)	1.46 (1.29-1.66)	1.05 (0.95-1.16)
Colorado	1.59 (1.42-1.79)	2.18 (1.91-2.5)	2.62 (2.35-2.92)	1.63 (1.43-1.86)	2.59 (2.38-2.81)	1.6 (1.48-1.73)
Connecticut	1.79 (1.55-2.05)	1.21 (1.04-1.4)	2.78 (2.27-3.4)	2.42 (2.02-2.91)	1.27 (1.1-1.47)	1.71 (1.57-1.87)
Delaware	1.03 (0.9-1.17)	1.21 (1.01-1.44)	1.71 (1.46-1.99)	0.98 (0.86-1.11)	1.86 (1.59-2.18)	1.16 (1.05-1.27)

Table 4 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Parent Perceived Spent Enough Time AOR (95 % CI)	Parent Perceived Receipt of Specific Information AOR (95 % CI)	Parent Perceived Showed Cultural Sensitivity AOR (95 % CI)	Parent Perceived Listened Carefully AOR (95 % CI)	Parent Perceived Felt Like a Partner AOR (95 % CI)	Final Overall Model AOR (95 % CI)
District of Columbia	1.02 (0.89-1.18)	0.9 (0.67-1.22)	0.93 (0.73-1.2)	1.33 (1.09-1.64)	0.82 (0.61-1.1)	0.98 (0.88-1.1)
Florida	0.83 (0.69-0.99)	0.79 (0.66-0.95)	1.15 (0.98-1.35)	1.28 (1.1-1.48)	1.04 (0.9-1.19)	1 (0.88-1.12)
Georgia	0.81 (0.7-0.94)	1 (0.83-1.21)	0.96 (0.84-1.1)	0.99 (0.86-1.13)	0.88 (0.76-1.02)	0.93 (0.85-1.03)
Hawaii	1.77 (1.53-2.05)	1.33 (1.13-1.55)	1.27 (1.05-1.53)	2.67 (2.09-3.41)	1.61 (1.32-1.97)	1.54 (1.35-1.75)
Idaho	0.88 (0.81-0.97)	0.72 (0.63-0.81)	0.94 (0.83-1.08)	1 (0.87-1.15)	1.08 (1-1.17)	0.97 (0.9-1.05)
Illinois	1.63 (1.47-1.79)	0.84 (0.75-0.94)	0.76 (0.67-0.85)	1.14 (0.99-1.32)	1.09 (0.99-1.2)	1.12 (1.05-1.19)
Indiana	0.94 (0.84-1.06)	1.4 (1.24-1.59)	1.51 (1.36-1.68)	1.51 (1.35-1.69)	1.53 (1.35-1.73)	1.06 (0.98-1.14)
Iowa	1.3 (1.17-1.44)	1.03 (0.89-1.19)	1.07 (0.93-1.22)	1.32 (1.16-1.5)	1.71 (1.49-1.95)	1.22 (1.13-1.31)
Kansas	1.29 (1.17-1.42)	1.02 (0.89-1.18)	1.44 (1.27-1.64)	1.12 (0.98-1.29)	1.22 (1.09-1.36)	1.21 (1.14-1.3)
Kentucky	1.04 (0.92-1.17)	0.78 (0.69-0.89)	1.04 (0.92-1.18)	1.38 (1.19-1.61)	1.18 (1.02-1.36)	1.13 (1.05-1.23)
Louisiana	0.83 (0.69-1)	1.12 (0.87-1.44)	1.32 (1.1-1.58)	1.82 (1.52-2.17)	1.2 (0.97-1.47)	1.01 (0.88-1.15)
Maine	1.49 (1.26-1.75)	1.31 (1.1-1.57)	1.83 (1.62-2.06)	1.69 (1.48-1.93)	1.36 (1.18-1.57)	1.26 (1.16-1.37)
Maryland	0.96 (0.84-1.1)	2.02 (1.77-2.3)	2.07 (1.77-2.42)	2.56 (2.2-2.96)	1.7 (1.42-2.03)	1.2 (1.09-1.32)
Massachusetts	1.13 (1-1.27)	0.76 (0.65-0.89)	0.88 (0.77-1.01)	0.91 (0.78-1.05)	0.99 (0.85-1.16)	1.18 (1.08-1.28)
Michigan	1.11 (0.99-1.24)	0.8 (0.66-0.97)	1.59 (1.39-1.82)	0.87 (0.76-0.99)	0.76 (0.65-0.89)	0.91 (0.84-0.98)
Minnesota	1.9 (1.74-2.08)	1.49 (1.27-1.75)	1.62 (1.41-1.85)	1.61 (1.4-1.86)	2.07 (1.76-2.43)	1.82 (1.72-1.92)
Mississippi	0.77 (0.69-0.87)	0.57 (0.45-0.74)	0.76 (0.64-0.9)	0.8 (0.68-0.93)	1 (0.82-1.22)	0.79 (0.72-0.86)
Missouri	0.88 (0.81-0.96)	1.1 (0.92-1.31)	0.9 (0.78-1.03)	1 (0.87-1.15)	1.16 (0.99-1.35)	1 (0.94-1.06)
Montana	1.02 (0.92-1.12)	0.93 (0.78-1.12)	0.91 (0.78-1.06)	1.29 (1.11-1.51)	0.95 (0.85-1.07)	1.03 (0.97-1.09)
Nebraska	0.93 (0.85-1.01)	0.84 (0.75-0.95)	1.69 (1.5-1.91)	1.72 (1.54-1.93)	1.03 (0.93-1.13)	1.06 (1-1.13)
Nevada	0.79 (0.71-0.88)	1.01 (0.85-1.18)	0.98 (0.87-1.11)	1.04 (0.91-1.2)	0.86 (0.78-0.95)	0.98 (0.91-1.06)
New Hampshire	1.58 (1.41-1.77)	1.61 (1.42-1.83)	1.28 (1.15-1.43)	1.1 (0.98-1.24)	1.23 (1.08-1.4)	1.21 (1.14-1.29)
New Jersey	1.64 (1.43-1.89)	1.88 (1.68-2.11)	1.89 (1.67-2.13)	2.06 (1.75-2.42)	1.25 (1.09-1.43)	1.42 (1.31-1.54)

Table 4 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Parent Perceived Spent Enough Time AOR (95 % CI)	Parent Perceived Receipt of Specific Information AOR (95 % CI)	Parent Perceived Showed Cultural Sensitivity AOR (95 % CI)	Parent Perceived Listened Carefully AOR (95 % CI)	Parent Perceived Felt Like a Partner AOR (95 % CI)	Final Overall Model AOR (95 % CI)
New Mexico	1.07 (0.91-1.25)	1.45 (1.17-1.79)	0.98 (0.8-1.19)	2.04 (1.66-2.5)	1.45 (1.27-1.66)	1.08 (0.97-1.22)
New York	1.89 (1.67-2.14)	2.06 (1.68-2.51)	2.48 (1.95-3.14)	2.23 (1.84-2.69)	2.25 (1.95-2.6)	1.66 (1.52-1.81)
North Carolina	0.73 (0.64-0.82)	0.9 (0.73-1.11)	1.31 (1.1-1.54)	1.52 (1.29-1.8)	1.22 (1.03-1.45)	0.95 (0.86-1.05)
North Dakota	1.07 (0.97-1.19)	0.92 (0.77-1.11)	1.31 (1.11-1.53)	1.14 (0.98-1.32)	1.2 (1.05-1.38)	1.16 (1.05-1.27)
Ohio	1.69 (1.48-1.94)	1.38 (1.18-1.61)	2.59 (2.29-2.93)	2.6 (2.28-2.97)	2.33 (1.98-2.74)	1.66 (1.54-1.79)
Oklahoma	1.14 (1.02-1.27)	0.97 (0.77-1.22)	0.81 (0.68-0.98)	0.79 (0.65-0.97)	1.07 (0.91-1.24)	1.11 (1.01-1.21)
Oregon	0.96 (0.85-1.09)	0.99 (0.89-1.09)	0.81 (0.73-0.9)	0.88 (0.77-1)	0.78 (0.71-0.86)	0.88 (0.8-0.96)
Pennsylvania	1.33 (1.13-1.57)	1.04 (0.83-1.3)	1.24 (1.04-1.48)	0.98 (0.82-1.15)	0.81 (0.68-0.98)	0.92 (0.82-1.03)
Rhode Island	1.06 (0.96-1.18)	0.97 (0.82-1.14)	1.1 (0.93-1.3)	1.21 (1.03-1.43)	0.94 (0.79-1.12)	0.98 (0.91-1.05)
South Carolina	1.06 (0.91-1.23)	1.1 (0.89-1.35)	0.78 (0.68-0.89)	1.6 (1.38-1.86)	1.59 (1.36-1.86)	0.97 (0.88-1.07)
South Dakota	0.86 (0.79-0.92)	1.54 (1.28-1.85)	2.07 (1.75-2.44)	2.44 (2.05-2.89)	1.77 (1.54-2.04)	1.24 (1.16-1.33)
Tennessee	1.27 (1.1-1.46)	1.72 (1.48-1.98)	2.94 (2.57-3.35)	2.18 (1.9-2.5)	1.89 (1.63-2.19)	1.5 (1.35-1.67)
Texas	0.98 (0.89-1.09)	0.88 (0.77-1)	0.65 (0.57-0.75)	1.11 (0.97-1.27)	0.88 (0.8-0.97)	0.87 (0.8-0.94)
Utah	Reference	Reference	Reference	Reference	Reference	Reference
Vermont	2.15 (1.67-2.75)	1.18 (0.98-1.42)	2.17 (1.87-2.51)	1.28 (1.07-1.55)	1.2 (1-1.45)	1.31 (1.14-1.51)
Virginia	0.8 (0.74-0.87)	1 (0.88-1.14)	0.94 (0.83-1.06)	0.8 (0.7-0.91)	0.75 (0.65-0.88)	0.85 (0.81-0.9)
Washington	1.06 (0.93-1.2)	0.65 (0.57-0.74)	0.97 (0.86-1.1)	0.83 (0.73-0.96)	0.85 (0.77-0.95)	0.9 (0.83-0.97)
West Virginia	1.09 (0.95-1.27)	1.8 (1.57-2.06)	2 (1.74-2.3)	2.3 (1.89-2.8)	1.46 (1.24-1.72)	1.28 (1.16-1.42)
Wisconsin	1.33 (1.23-1.45)	1.47 (1.29-1.68)	1.29 (1.16-1.44)	1.32 (1.19-1.47)	0.98 (0.84-1.14)	1.03 (0.98-1.08)
Wyoming	0.83 (0.78-0.89)	0.59 (0.52-0.67)	0.54 (0.48-0.61)	0.62 (0.55-0.7)	0.57 (0.52-0.63)	0.62 (0.6-0.65)
Adult Education						
Less than high school	Reference	Reference	Reference	Reference	Reference	Reference
High school degree or GED	1.26 (0.85-1.88)	0.81 (0.37-1.77)	0.62 (0.32-1.22)	0.81 (0.42-1.57)	0.72 (0.35-1.47)	0.98 (0.65-1.48)

Table 4 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Parent Perceived Spent Enough Time AOR (95 % CI)	Parent Perceived Receipt of Specific Information AOR (95 % CI)	Parent Perceived Showed Cultural Sensitivity AOR (95 % CI)	Parent Perceived Listened Carefully AOR (95 % CI)	Parent Perceived Felt Like a Partner AOR (95 % CI)	Final Overall Model AOR (95 % CI)
Some college or technical school	1.23 (0.79-1.92)	0.74 (0.34-1.64)	0.64 (0.35-1.15)	0.69 (0.43-1.12)	0.65 (0.35-1.18)	0.96 (0.7-1.32)
College degree or higher	1.2 (0.66-2.17)	0.94 (0.45-1.94)	0.77 (0.46-1.28)	0.72 (0.46-1.15)	0.6 (0.36-0.99)	0.97 (0.62-1.54)
Sex of Adult						0
Male	0.86 (0.73-1.03)	0.83 (0.61-1.13)	0.97 (0.77-1.22)	0.75 (0.62-0.91)	0.94 (0.79-1.12)	0.89 (0.78-1)
Female	Reference	Reference	Reference	Reference	Reference	Reference
Mother Health Status						0
Physical & mental health BOTH excellent/very good	Reference	Reference	Reference	Reference	Reference	Reference
One or both of physical & mental health are NOT excellent/very good	0.7 (0.53-0.94)	0.72 (0.59-0.88)	0.88 (0.74-1.04)	0.65 (0.51-0.83)	0.68 (0.58-0.8)	0.72 (0.59-0.88)
No mother reported in the household	1.19 (0.38-3.78)	1.05 (0.42-2.66)	1.08 (0.54-2.15)	1.03 (0.47-2.24)	1.15 (0.58-2.28)	1.22 (0.5-2.97)
Parent Nativity						
Parent(s) born in US	Reference	Reference	Reference	Reference	Reference	Reference
Any parent born outside US	0.82 (0.61-1.1)	0.76 (0.51-1.15)	0.75 (0.46-1.23)	0.84 (0.6-1.16)	0.74 (0.57-0.95)	0.76 (0.65-0.88)
Father Health Status						0
Physical & mental health BOTH excellent/very good	Reference	Reference	Reference	Reference	Reference	Reference
One or both of physical & mental health are NOT excellent/very good	0.99 (0.76-1.3)	0.77 (0.64-0.93)	0.66 (0.49-0.89)	0.71 (0.54-0.93)	0.67 (0.55-0.82)	0.88 (0.73-1.06)

Table 4 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Parent Perceived Spent Enough Time AOR (95 % CI)	Parent Perceived Receipt of Specific Information AOR (95 % CI)	Parent Perceived Showed Cultural Sensitivity AOR (95 % CI)	Parent Perceived Listened Carefully AOR (95 % CI)	Parent Perceived Felt Like a Partner AOR (95 % CI)	Final Overall Model AOR (95 % CI)
No father reported in the household	1.4 (0.69-2.83)	1.18 (0.46-3.01)	1.03 (0.62-1.71)	1.03 (0.48-2.17)	1.2 (0.67-2.13)	1.25 (0.7-2.25)
Child Race/Ethnicity						0
White, non-Hispanic	Reference	Reference	Reference	Reference	Reference	Reference
Hispanic	0.81 (0.63-1.05)	0.91 (0.63-1.33)	1.31 (1.02-1.68)	1.03 (0.78-1.36)	1.09 (0.8-1.48)	1.03 (0.89-1.19)
Black, non-Hispanic	0.68 (0.57-0.81)	1.25 (0.81-1.93)	1.23 (0.95-1.59)	1.38 (0.99-1.94)	1.35 (0.98-1.86)	0.87 (0.74-1.03)
Asian, non-Hispanic	0.97 (0.67-1.41)	0.52 (0.36-0.76)	0.74 (0.46-1.17)	1.82 (0.9-3.68)	0.58 (0.4-0.86)	0.84 (0.68-1.04)
American Indian or Alaska Native Non-Hispanic	0.57 (0.17-1.88)	0.39 (0.15-1.04)	0.7 (0.32-1.51)	0.78 (0.27-2.27)	0.84 (0.35-2.02)	0.58 (0.21-1.55)
Native Hawaiian and Other Pacific Islander Non-Hispanic	0.72 (0.13-4.12)	0.45 (0.09-2.22)	0.29 (0.08-1.08)	0.46 (0.09-2.28)	0.72 (0.12-4.22)	0.66 (0.16-2.78)
Multi-Race Non-Hispanic	1.27 (0.89-1.8)	0.95 (0.65-1.39)	0.92 (0.61-1.39)	1.32 (0.92-1.89)	0.99 (0.69-1.41)	1.17 (0.86-1.59)
Other Non-Hispanic	3.12 (1-9.72)	7.72 (1.88-31.71)	4.61 (0.99-21.45)	11.1 (1.93-63.92)	1.94 (0.54-7.02)	2.16 (1-4.69)

Mother/father health status and Sex of Adult

The significance of the mental and physical health of the mother and father as a predictor of PFCC varied by model. In the "final overall" model, mothers with a physical and mental health condition had 28% lower odds of receiving higher levels of PFCC than those with excellent mental and physical health. The “spent enough time” model (30% lower), “provided specific information” model (28%), “listened carefully” model (35%), and “felt like a partner” model (32%) all showed significantly lower odds of receiving those components of PFCC for mothers with physical and/or mental health conditions when compared to mothers with both excellent/very good physical and mental health. This predictor was not significant for the “showed cultural sensitivity” model. Father’s physical and mental health was not significant to the receipt of PFCC in the "final overall" model or “spent enough time" model. However, it was significant in the “provided specific information” (23% lower), “showed cultural sensitivity” (34% lower), “listened carefully” (29% lower), and “felt like a partner” (33% lower) models. These models showed lower odds of receiving those components of PFCC if a father had a mental or physical health condition. The only model that was significant for the sex of the adult was the “listened carefully” model, in which adult males had lower odds of receiving this component (25% lower).

Insurance type

Insurance type was a significant predictor in receiving higher levels of PFCC in the "final overall" model for those that were currently uninsured. This population had 24% lower odds of receiving higher levels of PFCC compared to those who had private insurance only. In the five component models, results varied greatly. In the “spent enough time”, “showed cultural sensitivity”, and “listened carefully” models, insurance type was not a significant predictor of receipt of those components of PFCC. In the “felt like a partner” model, those with public and private insurance had

30% lower odds of feeling like a partner in their care than those with private insurance only. For the "provided specific information" model, those with both public and private insurance (36% lower) and those currently uninsured (49% lower) had lower odds of receiving this component of PFCC than those with private insurance only.

Usual place of sick care

Place of usual sick care was significant in the "final overall" model. Children who usually obtain their sick care from a hospital outpatient department (60% lower), clinic or health center (26% lower), or a retail store clinic or minute clinic (59% lower) had lower odds of receiving higher levels of PFCC compared to those who obtained their sick care from a doctor's office. In the component models, the hospital outpatient department was significant in the "spent enough time" (67% lower), "provided specific information" (78% lower), and "showed cultural sensitivity" (74% lower) models when compared to sick care obtained from a doctor's office. Clinic or health center was only significant in two of the component models, "listened carefully" (36% lower), and "felt like a partner" (32% lower) when compared to sick care obtained from a doctor's office. Retail store clinic or minute clinic was significant in the "provided specific information" (69% lower), "showed cultural sensitivity" (69% lower), "listened carefully" (75%), and "felt like a partner" (32%) models when compared to sick care obtained from a doctor's office. Sick care obtained at some other place was only significant in the "listened carefully" model (71% lower) when compared to sick care obtained from a doctor's office.

Personal nurse or doctor

The results for the usual source of sick care are consistent with the findings for children who do not have a personal nurse or doctor. In the "final overall" model, children who do not have a personal nurse or doctor had 53% lower odds of receiving higher levels of care than those with a personal nurse or doctor. All component models also showed significance for this predictor when compared to those who had a personal nurse or doctor; “spent enough time” (57% lower), “provided specific information” (57% lower), “showed cultural sensitivity” (55% lower), “listened carefully” (56% lower), and “felt like a partner” (60% lower).

Federal Poverty Level

The federal poverty level was a significant predictor in all models. For the “overall final” model, all FPLs were significant in predicting if a child/family would move to a higher-level of care. In the binary component models that looked at the odds of receiving that type of care component, results varied. Those at 0-99% of the FPL had lower odds of receiving cultural sensitivity, being listened to carefully, and feeling like a partner in their care. For those at 100-199% of the FPL, they had lower odds of spending enough time with their providers or being listened to carefully. For those at 200-399% of the FPL, they had lower odds of spending enough time with their providers, being provided specific information, or feeling like a partner in their care.

Household language, child/parent nativity, family structure

Household language was only significant in the "final overall" model (26% lower) and the “spent enough time” model (31% lower) which suggests that children in households with a primary language other than English have lower odds of receiving higher levels of PFCC and are less likely to spend enough time with their health care providers. Parent nativity was a significant predictor of PFCC (24% lower) in the "final overall" model and “felt like a partner” model (26% lower) when compared to those born in the US. This suggests that those children with parents who are born outside of the United States have greater odds of not receiving higher levels of PFCC and lower odds of feeling like a partner in their own care. Conversely, child nativity was only significant in the “spent enough time” model (74% higher) which suggests that children who were born outside of the United

States have 74% greater odds of spending enough time with their health care provider. Children from single-parent households had lower odds of receiving three components of PFCC, “showed cultural sensitivity” (48% lower), “listened carefully” (54% lower), and “felt like a partner” (49% lower).

Race/Ethnicity

Unadjusted models showed that those who identified as Asian, Black, or Hispanic had significantly lower odds of receiving higher levels of PFCC. Race/ethnicity was not a significant predictor for any race/ethnicity in the adjusted "final overall" model. Those who identified as Asian had a significant association in the “provided specific information” model (48% lower) and the “felt like a partner” model (42% lower). Those who identified as Black had a significant association with PFCC in the “spent enough time" model (32% lower). The “showed cultural sensitivity” model just past the threshold to be significant for those who identified as Hispanic (AOR 1.31, CI [1.02, 1.68]). This would suggest that those who identified as Hipsanic were 31% more likely to receive PFCC, which would require further investigation to confirm or interpret. No other race/ethnicity had a significant association in any component models.

State of residence and school/neighborhood safety

Patterns can be seen in the relationship between PFCC and the state in which the child lives. Wyoming, Mississippi, Alabama, and Virginia were consistently in the lowest five states for the receipt of higher levels of PFCC and receipt of its components (Table 5). There were also five states consistently among the top five performing states: New York, Ohio, Colorida, Minnesota, and Connecticut. School and neighborhood safety were both significant in all models for those that somewhat agreed, somewhat disagreed, and definitely disagreed that their neighborhood or school was safe.

Table 5

States with highest and lowest odds of receiving PFCC and individual PFCC components

Model	Highest Odds	Lowest Odds
Overall Model	Minnesota (1.82)	Wyoming (0.62)
	Connecticut (1.71)	Alabama (0.74)
	New York (1.66)	Oklahoma (0.79)
	Ohio (1.66)	Mississippi (0.80)
	Colorado (1.60)	Virginia (0.80)
Listened Carefully Model	Hawaii (2.67)	Wyoming (0.62)
	Ohio (2.60)	Alabama (0.74)
	Maryland (2.56)	Oklahoma (0.79)
	South Dakota (2.44)	Mississippi (0.80)
	Connecticut (2.42)	Virginia (0.80)
Spent Enough Time Model	Vermont (2.15)	Alabama (0.71)
	Minnesota (1.90)	North Carolina (0.73)
	New York (1.89)	Mississippi (0.73)
	Connecticut (1.79)	Nevada (0.79)
	Hawaii (1.77)	Virginia (0.80)
Provided Specific Information Model	Colorado (2.18)	Mississippi (0.57)
	New York (2.06)	Wyoming (0.59)
	Maryland (2.02)	Alabama (0.62)
	New Jersey (1.88)	Washington (0.65)
	West Virginia (1.80)	Idaho (0.72)
Showed Culturally Sensitive Model	Tennessee (2.94)	Wyoming (0.54)
	Connecticut (2.94)	Texas (0.65)
	Colorado (2.62)	Mississippi (0.76)
	Ohio (2.59)	Illinois (0.76)
	New York (2.48)	Alabama (0.76)
Felt like a Partner Model	Colorado (2.59)	Wyoming (0.57)
	Ohio (2.33)	Virginia (0.75)
	New York (2.25)	Michigan (0.76)
	Minnesota (2.07)	Oregon (0.78)
	Tennessee (1.89)	Pennsylvania (0.81)

Discussion

This study used logistic regression to examine predictors in the receipt of PFCC for children/families in the U.S. It was conducted to provide researchers, funders, training programs, advocates, and health professionals with information to help improve the quality of care received by children/families. Of the final sample, after exclusion criteria, 95% of children/families received four or five components of PFCC. However, despite the high overall rates of PFCC receipt, disparities remain for certain populations.

Similar to other studies about PFCC and child health, this study shows a relationship between higher levels of PFCC and child health (Kuo et al., 2011; Montes & Halterman, 2011). This relationship suggests that CSHCN or CLEH have lower odds of receiving each component of PFCC and lower levels of PFCC overall. While a qualitative follow-up to better understand the rationale for this relationship is needed, it is possible that these populations need more from their providers than those without special health care needs or those who are in excellent health. Additionally, mother's and father's health status was significantly associated with the child/family's receipt of PFCC and need to be considered when providing care to the child. These families might have more questions, need additional resources or support systems, and rely on their providers more heavily. Providers may not have the training needed to help families with SHCN or who are in poorer health or they may not be given the time they need to help their patients by the health system in which they work. To more fully understand this concern and the barriers to PFCC for this population, a provider and health system perspective would be valuable.

It is possible that CSHCN and CLEH interact with a larger number of distinct providers, interact with providers more often, and have different needs from providers than those without a SHCN or who are in excellent health. These children/families may have a better understanding of the spectrum of quality of care and be more aware of when they are not receiving high-quality care from a provider. This may lead to lower scores of PFCC for CSHCN and CLEH; however, no less accurate to the experience of the child/family. It reflects the limitations of perception-based data collection since all of the respondents do not have the same amount or diversity of experiences with providers.

These children/families may also be seeing a primary care provider for needs that a specialist is better suited to address (Huang et al., 2020).

The usual source of sick care and whether a child has a personal doctor or nurse point to the importance of consistency in care. This study was consistent with the literature in finding that having a usual source of sick care and having a personal doctor or nurse is associated with receiving higher levels of PFCC (Kuo et al., 2011; Smalley et al., 2014). However, consistency itself is not enough. The health care facility type is also important. This is especially true for CSHCN who have higher rates of usual sources for sick care but also use the hospital more often for care. The current study, along with others, found that hospital use as a usual source for care was found to be associated with lower odds of receiving higher levels of PFCC (Coller et al., 2016; Kuo et al., 2011). This makes sense because those who consistently see a provider in a location that has their patient history and knows their patient well, would be better equipped at providing a higher-quality of care.

For CSHCN or CLEH, it may be challenging to receive all of their care in the same location and with the same providers. Programs should be developed or strengthened to train and equip more primary care providers and hospitals to help CSHCN and CLEH. There should be a strong focus on creating a medical home for the child where a team of providers work together to provide the best care possible regardless of if the providers are working for the same health system (Kan et al., 2016; Singh et al., 2009). Additionally, disparities exist for having a usual source of sick care and personal doctor or nurse that are related to inadequate insurance coverage, ethnicity, household language, lower levels of income, and region of the country (Coker et al., 2010; Kogan et al., 2010; Parish et al., 2013; Singh et al., 2009). This is important to consider when conceptualizing the problem holistically and trying to find solutions.

Health systems may also play a larger role than can be examined by this study. While health systems are designed to support the care of patients, as a business, they must consider profit and effectiveness. They may have an approach for how to interact with patients, the amount of time given to each patient, and other factors that impact their providers’ ability to deliver high-quality care. These approaches may be at the macro-level as an organization or at a micro-level within specific departments. For example, the difference between the approach and culture of an emergency department vs. a children's unit. For those with more complex needs, the approach that a health system takes in interacting with patients may not meet their needs. For example, in the short-term, it may not appear to be profitable to spend more time with a patient or take time to provide them specific information. It may appear more efficient for the provider to use the information they have to tell the patient what to do and hope that the patient understands and takes their advice. This study is not able to confirm any of the above possibilities due to the limitations of the nature of this study. The patient voice, observational data, and an experimental mixed-methods study design are needed to explore these possibilities further.

Where someone seeks care is related to their insurance type and income, which are two other important predictors that were significantly associated with PFCC in this study. Those who made less than 400% of the FPL had higher odds of not receiving high levels of PFCC when compared to those that made 400% or more of the FPL. This was consistent with other studies of PFCC that found those in lower FPLs to have lower odds of having a personal doctor or nurse and receiving PFCC (Coller et al., 2016; Montes & Halterman, 2011; Smalley et al., 2014; Azuine et al., 2015). In the current study, families who were uninsured had 24% lower odds of receiving higher levels of PFCC in the "final overall" model. In the binary component models, insurance type was only significant in the “provided specific information” model. This varies from previous studies that found those who had public insurance or who were uninsured were dissatisfied with their care and received less PFCC overall and by component. The conflicting results need to be studied more in-depth. Overall results suggest that having health insurance of any kind is a protective factor for receiving PFCC. There are many programs that help to ensure children have health insurance. Policymakers should work with schools to increase the awareness of these programs and ensure that children have some type of health insurance coverage. For families that fall into insurance gaps, policymakers should explore Medicaid expansion and develop other assistance programs or public policies.

Children/families in single-parent households were associated with lower odds of receiving cultural sensitivity, being listened to carefully, and feeling like a partner with their healthcare providers. Smalley et al found similar results with single mother households and shared decision making, which is part of the child/family feeling like a partner in their healthcare (2014). Parish et al also found that single mothers of children with SHCN were less likely to receive PFCC (2013). Single parents may have different needs from their health care provider than other families. A qualitative follow-up would be helpful to understand the specific needs of this population. Providers should have additional training on how to best support single-parent households. Care coordination efforts should be considered to help provide additional support that goes beyond the scope of the health care provider.

Racial and ethnic disparities are common in many health-related studies (Montes & Halterman, 2011; Smalley et al., 2014). This study paid special attention to PFCC for POC. While disparities were seen in the unadjusted overall model for people who identified as Asian, Black or Hispanic, they were not significant after model adjustments for predictors, which was unexpected but consistent with Bleser et al (2017). The "final overall" model was significant for those who identified as Asian with all predictors except parent nativity, which explained the largest association between

PFCC for this population. Neighborhood safety, school safety, and FPL explained the variance that made the results for those who identified as Hispanic significant in the unadjusted model. Family structure explained much of the variance for those who identified as Black. These results point to the effects of history that are still felt today and current larger systemic issues. For example, racial and ethnic discrimination in public policy, law, banking, real estate, and zoning.

Component models yielded similar results but showed more significant associations for POC than in the "final overall" model. In the “spent enough time” model, those who identified as Black had 32% greater odds of their provider not spending enough time with them. This might be indicative of challenges that Black POC experience and could be related to higher rates of morbidity and mortality for this population (Flores & the Committee on Pediatric Research, 2010). Showing cultural sensitivity just reached the threshold to be significant for those who identified as Hispanic (AOR 1.31, CI [1.02-1.68]) and was not significant for any other racial or ethnic group. It is possible that this construct is not clearly defined and answering this question is therefore difficult for respondents. More clearly defined constructs or examples could be used in the future in addition to adding questions about discrimination, similar to survey questions asked on the PRAMS (Almeida et al., 2022). The “provided specific information” model and “felt like a partner” model only showed significant results for those who identified as Asian. These results were unexpected, as other populations were theorized by this study to also have lower odds of receiving those components of PFCC based on the previous literature. Smalley et al found that all non-white races/ethnicities had increased odds for not receiving shared decision making (2014). Azuine et al found that those who identified as Black or Hispanic were found to have higher odds of not receiving PFCC when compared to families who identified as white (2015); this was especially true for parents with CSHCN who identified as Black (Montes & Halterman, 2011). It is possible that differences in the covariates selected for inclusion or differences in statistical approaches could account for differing results for the current study when compared to the previous literature. The current study also included eight groups for race/ethnicity, which differs from previous studies and may explain some differences in results. Further exploration and study is needed.

Non-English language households had 26% lower odds of receiving higher levels of PFCC and 31% lower odds of their provider spending enough time with them. Azuine et al found that in non-English language households, children and families had over two times greater odds of not receiving PFCC or of their health care providers spending enough time with them (2015). If English is not spoken fluently by the family and the provider, it can make health visits difficult (DeCamp et al., 2013). A possible explanation could be that, although it is not best practice and has many ethical concerns, family members or friends often act as translators between a loved one and their health care provider (Kuo et al., 2007). Providers and patients may also find it difficult to ensure that there is a common understanding of the problem or be given the extra time that the visit may require due to possible language barriers. Future research should explore the household language outcome further to better understand its unique challenges and find possible solutions. Policymakers and programs should work with researchers to implement support for families that do not speak English fluently in order to increase the quality of care that they receive (Dudley et al., 2015; McDonough et al., 2004).

One predictor that this study wanted to consider was the importance of where the child/family lives. Results from three predictors that were related to location confirmed a significant relationship with PFCC. School safety and neighborhood safety suggest that those living in neighborhoods or attending schools that they do not believe are safe have lower odds of receiving PFCC than those who definitely agreed that their neighborhoods and schools were safe. It is possible that high-quality care is not available in areas that are considered unsafe or that there are additional systemic issues acting as a mechanism for these disparities. Interpreting this result is difficult without more information and should be considered within a larger context to examine the child/family holistically. The state in which a child/family lives also had a significant relationship with PFCC. States that were consistently in the top five for PFCC from model to model should be studied to understand what policies, programs, and other factors are providing protective factors for their residents. States should work together to build partnerships and share information with one another to strengthen their ability to provide higher levels of PFCC to the children/families in their state. Consistent with other studies, the southeastern region of the U.S. appears to have the lowest receipt of PFCC. Health policies, supportive programs, provider training programs, public policies, and funding in these states might differ from other states and should be studied further.

Although this study included many important predictors, it was only able to account for a small amount of the variance in the receipt of PFCC. This may be due to factors at many different levels of influence. It is important not to place blame on any one level and instead understand what challenges each one faces. For example, it is unlikely that providers knowingly choose to provide lower levels of care to patients. It is more likely that they do not have the needed training, are not supported by their health system to do so, are experiencing burnout, or other factors. Future studies should include qualitative follow-up or measures of health provider wellness, cultural competency, knowledge of PFCC and how to provide it, and how supported/equipped they feel in delivering PFCC by their workplace.

Limitations & Future Directions

This study has several limitations which are important to note both for context and to help inform future research in this area. First, the NSCH is a cross-sectional survey. All results from studies that use this type of non-experimental data can only study associations and may not make causal inferences. Results from this study should be viewed as preliminary until other data sources and studies have verified similar findings. Additional data sources or variables to include that could be helpful are video/audio recordings from visits, health system staff and provider questionnaires, qualitative data collection of child/family experiences and of providers/health systems, data that includes the number of different providers seen in the last year, number of visits in the last year, etc. While some of this data is very sensitive in nature and may be difficult to obtain, it would provide more insight into the challenges of delivering high-quality care, especially to those less likely to receive it. This is important because without having external perspectives, observations of these interactions, and other important data sources, it is difficult to separate provider actions from the perceptions of the respondent. This makes causal direction unclear. Additionally, respondent perceptions are only studied quantitatively here, which limits their usefulness because they are missing the patient voice. It may be that those who have more experience interacting with a range of providers have a more clear understanding of the spectrum of quality of care than those with less need to interact with providers as often.

Second, the PFCC outcome measure is assessed using a subjective 4-point Likert Scale. What is considered “often” or “always” may differ by respondent. The NSCH could add a reference for what they consider “never”, “sometimes”, “often”, and “always”. Likewise, the constructs inherent in some of the PFCC questions are subjective; for example, how a patient decides if they were provided culturally sensitive care. The questions are not broken down to provide examples or more information to help the respondents understand the criteria for the question. The NSCH could list small examples in future versions of the survey.

Third, the low variability in results for PFCC could an indication of the NSCH’s lack of sensitivity to measure PFCC, thus resulting in the underrepresentation of disparities for the receipt of

PFCC. Stronger survey measures should be added to the NSCH or used in place of the NSCH when studying PFCC in the future.

Fourth, another important consideration is that the NSCH relies on the recall of all visits to a healthcare provider in the last year for one child. This is challenging for a few reasons: a year is a long recall period that could yield unreliable responses; reliance on respondents recalling visits for a particular child rather than for a different child or themselves may be difficult; all providers are rated in one question; and provider type is not considered. It is possible that the most recent or most helpful/unhelpful visits are most easily remembered and reported. Future research could employ a mixed-methods approach to follow up with doctors and patients post-appointment to gather qualitative data after a brief quantitative questionnaire is completed or allow for observational data collection. Collecting data post-visit could also be helpful in reducing recall time and increasing the reliability of the data.

Fifth, while one important consideration of this study was exploring race/ethnicity and PFCC more closely, the NSCH only includes the race/ethnicity of the child. The caregiver’s race/ethnicity may also play a role in the receipt of PFCC and should be explored. The addition of an item about caregiver race/ethnicity could be helpful to provide more insight into disparities by race/ethnicity, among other subjects of interest. Additionally, questions like those in other national surveys could be added to directly address discrimination experienced with a provider for POC (Almeida et al., 2022).

Sixth, another consideration is imputation of data. Imputation is a powerful tool in studying health but it is not without its limitations (Greenland & Finkle, 1995). The NSCH uses imputation for missing child sex, race, ethnicity, adult education, FPL, and household size, which may limit the accuracy of study results despite support for the use of imputation (Zavez et al., 2022). There may also be ethical considerations in a computer model assuming something as personal as an individual's choice in how they identify their race/ethnicity. Contrastly, there are ethical concerns for not including imputed race/ethnicity data (National Research Council (US) Panel on DHHS Collection of Race and Ethnic Data, 2004). The NSCH uses multiple imputation, which is considered the most methodologically rigorous form of imputation. All information about imputed data can be found in their methodology reports, which are separated by year (U.S. Census Bureau, 2019).

Seventh, there are many predictors that cannot be controlled for or examined in this study. This includes predictors about the providers, health systems, local community, health programs, provider training programs, number of providers by state, state policies, etc. Seventh, non-random error may be present in the NSCH, including non-response bias. The NSCH is analyzed each survey year to assess for non-response bias. Their reports for 2018-2019 found that there was no strong evidence of nonresponse bias once they applied the survey weights (U.S. Census Bureau, 2020). Some non-response was found in populations with more POC populations, households with lower socioeconomic status, less homeownership, and lower levels of education. This points to the possibility of non-response bias, but was not consistent, which led the NSCH to conclude that if there was any bias, it was small (U.S. Census Bureau, 2020). Only finding a small possible non-response bias is likely due to the efforts they take to prevent non-random error, including random selection, item question testing, confidentiality assurances to respondents. These efforts have been reviewed by the National Quality Forum and the survey has been approved for its validity (Data Resource Center for Child and Adolescent Health, 2011; U.S. Census Bureau, 2019).

Lastly, this study’s sample was restricted to children who had a visit with a healthcare provider in the last 12 months and thus did not have a logical skip to answers about PFCC. Those who have had negative experiences with healthcare providers may be less likely to have sought care in the last 12 months, which would make the sample skewed towards those who have more positive experiences with their healthcare providers. This is also important to consider for those that are not able to access care due to other barriers and were not able to answer questions because they also did not have a visit within the last 12 months.

Conclusion

This study used more recent data than previous studies and focused on the state more heavily than in most previous studies. It found many predictors that are significantly associated with the child's/family's receipt of PFCC. These included special health care status, overall health status, insurance type, usual source of sick care, having a personal doctor or nurse, household language, school and neighborhood safety, FPL, mother's health status, parental nativity, and state. While there is practical significance to these findings, further research is needed that can help to explain the associations found in this study that go beyond a secondary quantitative study design. Despite attempts to strengthen the methodological rigor of previous studies; ultimately, this study was only able to explain 7% - 12% of the receipt of PFCC, depending on the model. This suggests that further studies that take a different approach are needed. Due to the nature of a secondary study, the current study is unable to explain these results further nor move past the study of disparities in order to focus on the mechanisms for these disparities aside from conceptualizing the family holistically.

A mixed-methods approach could be used to help unpack respondent answers to quantitative questions. Study designs could include the child/family's voice, provider perspective, health system-level perspective, and a study of public policies. This type of approach is important to understanding protective factors and barriers in the receipt of PFCC more fully. By doing so, we can understand mechanisms that create disparities, reduce disparities in the quality of care received and health outcomes, and increase the quality of life for our youth and their families. Until the research is furthered in this area, this study can help provide insight into which aspects of PFCC are less likely to be received and by whom as well as any protective factors for receiving PFCC to aid researchers, grantors, states, and health programs in decision making and planning.

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Exploring State Differences in the Receipt of Patient/Family-centered Care

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Abstract

OBJECTIVES: The aims of this study were to determine the extent to which variability in PFCC exists within states vs. between states, identify the highest and lowest performing states, and understand PFCC's relationship to child health utilizing the National Survey of Children's Health (NSCH).

METHODS: Caregivers of 38,803 non-institutionalized children, aged 0 to 17 years, were surveyed by the NSCH 2018–2019. A continuous composite variable for PFCC was defined by five questions that were answered on a Likert scale from always to never. Questions included if the provider spent enough time with the family, showed cultural sensitivity, provided specific information, made the family feel like a partner in their child's care, and listened carefully to the family. Multilevel modeling and linear regressions were analyzed and results were mapped.

RESULTS: Ninety-one percent of the sample population received PFCC. Children with special health care needs (CSHCN), children with less than excellent health (CLEH), the uninsured, those who received sick care from somewhere other than a doctor's office, were from households with less than 400% FPLs, were from unsafe neighborhoods or unsafe schools, or had mothers with health concerns had significantly lower amounts PFCC. PFCC varied by state but receipt of PFCC was mostly explained by within-state differences. In an unadjusted MLM, those who identified as Hispanic, Black, American Native/ Pacific Islander, or Multiracial had significantly lower amounts of PFCC; however, after adjustments, no race/ethnicity had significant results. Additionally, many states, particularly in the southeastern region, showed disparities for receiving PFCC. The lowest-performing states were Wyoming, Alabama, Mississippi, Virginia, and Nevada. In contrast, New York, Ohio, Colorado, Minnesota, and Hawaii were the highest-performing states.

CONCLUSION: The final PFCC model was only able to explain 6% of the variability in receipt of PFCC for the full sample population. Further exploration by geography and for specific populations is needed. Future research should consider smaller geographic regions, health systems, state policies and programs, and include the patient, provider, and health system voice via a mixed-methods design.

KEYWORDS: family-centered care; patient/family-centered care; National Survey of Children’s Health; United States

Exploring State Differences in the Receipt of Patient/Family-centered Care

Where we work, live, play, learn and grow are important factors in understanding health outcomes and disparities for children (Singh et al., 2009; Baicker et al., 2005; Fisher-Owens et al., 2016). In the United States, health disparities can be seen between states in the quality of care received, access to care, insurance status, and health outcomes (Azuine et al., 2015; Bethell et al., 2011; Singh et al., 2009). Some examples of these state variations include children without insurance ranging from 5.7% in Massachusetts to 26.2% in Texas (Bethell et al., 2011); and children living in Virginia, Nevada, California, Florida, New York, Arizona, and Mississippi have 1.51 times higher adjusted odds of not receiving high-quality health care than those living in Vermont (Azuine et al., 2015).

Health disparities between states may be linked to many factors (Azuine et al., 2015; Bethell et al., 2011). First, states can vary widely in insurance access, options, and availability (Zickafoose et al., 2012). Public and private health insurance markets are determined at the state level by regulations to primary care, state-funded health programs, state-based decisions to expand Medicaid, and other factors (Zickafoose et al., 2012). Some states have decided not to adopt Medicaid expansion which has created a health coverage gap with no feasible way for residents of that state to access insurance (Garfield et al., 2021). Most states who have not accepted federal funds for Medicaid are located in the southeastern region of the United States (Kaiser Family Foundation, 2021). For states that have adopted Medicaid expansion, many have not begun implementation (Taylor, 2019). Private insurances have become more consistent from state to state since the Affordable Care Act but options and average premiums vary greatly (Kaiser Family Foundation, 2020). For example, average premiums range from $307 per month in Minnesota to $791 per month in Wyoming (Kaiser Family Foundation, 2020). Second, states have different health priorities. Each state’s health priorities, in the form of state performance and outcome measures, health programs and policies, etc., are determined by state health departments and legislators (Institute of Medicine (US) Committee, 1988; Remington 2015). Third, there is high variability in the number of existing programs and policies that support health equity by state which supports studying health with consideration of geographic location (National Conference of State Legislatures, 2014). Lastly, there are many other known and unknown factors that are likely to influence health disparities between states that go beyond the scope of this study (Belanoff et al., 2012; Lin et al., 2012).

Another layer to health disparity that extends beyond state differences, but may be exacerbated by state contextual factors, are disparities for specific populations. These differences can be seen in health access, quality, and outcomes for people of color (POC), children with special health care needs (CSHCN), and children with less than excellent health (CLEH). These populations, which are not mutually exclusive, are more likely to experience higher rates of morbidity and mortality than other groups (Brannon et al., 2021; Feagin & Bennefield, 2014; Flores & the Committee on Pediatric Research, 2010; Newacheck et al., 2008; Williams & Mohammed, 2009). Despite the variation in health policies, priorities, access, and disparities by state, little research has examined the between-state differences in the receipt of high quality of care for these populations. Doing so continues to laying the groundwork for future research to move beyond disparities and explore systemic inequities that act as a mechanism for disparities between states (Azuine et al., 2015; Guerrero et al. 2010; Hsu et al., 2019; Singh et al., 2009; Zickafoose et al., 2012).

For the purposes of this study, patient/family-centered care (PFCC) is used to measure the quality of care received. This measure of the quality of care was chosen because it can also be used as a method of delivering care that can help to reduce health disparities for the populations of interest (Gance-Cleveland, 2006; Kuo et al., 2011). Previous studies of PFCC have examined sociodemographic characteristics or focused on specific subpopulations (e.g. children with special health care needs, specific health conditions, countries of origin) but have had little focus on the respondent's location (Kan et al., 2016; Montes & Halterman, 2011; Zajicek-Farber et al., 2017). Kan et al. (2016) found that disparities in the medical home presence and family-centered care (FCC) for CSHCN appeared to be increased when children have parents who are foreign-born. Children who identified as Black with autism spectrum disorder (ASD) had two to five times greater odds of not receiving FCC as compared to children who identified as white without ASD (Montes & Halterman, 2011). Zajicek-Faber et al. (2017) studied FCC's relationship to race/ethnicity and found that families of color reported receiving less FCC in community coordination, follow up, care setting practices, policies, and less satisfaction with medical homes for their child with SHCN when compared to families who identified as White. Although these findings are extremely valuable and highlight racial/ethnic disparities, families are not disentangled from their state's contextual factors (e.g. culture of the state, health policies, exposures and experiences shared by people that live in the same state, insurance options, and availability, etc.). This approach doesn't address systems-level barriers and can sometimes frame the child/family's demographic characteristics as the mechanism for the difference in care quality rather than looking for systemic inequities.

One study did consider the difference in receipt of PFCC by state. Azuine et al. examined the odds of a child/family receiving PFCC for each of the components of PFCC by state while controlling for sociodemographic characteristics (2015). State of residence was included in a regression model and predictors were disaggregated by state as well as each component of PFCC. Results showed that children in the southern and western parts of the United States and children of color were less likely to receive PFCC. The approach of adding state and disaggregating by it was an important step in strengthening the methodological rigor in the study of PFCC; however, it does not consider families being nested within states and relies on a reference state for analysis. State comparisons bring valuable insights but can be improved by removing the use of a reference state. Using this method allows for a more meaningful interpretation and does not require that one state be the benchmark for all comparisons but rather examines differences between many states simultaneously.

The current study improves upon previous research by including Asian as a race category, providing a frame that focuses on the system instead of the individual as the mechanism for disparities, and by employing a statistical analysis that does not require a reference state. Additionally, this study clearly defines and disaggregates caregiver education and child race/ethnicity, and provides heat maps of the receipt of PFCC.

Multilevel modeling (MLM) was employed to assess the family's receipt of PFCC utilizing the National Survey of Children's Health (NSCH). The NSCH was designed to learn about families' experiences in utilizing the healthcare system, the health and well-being of children, and to understand how state and national performance measures are perceived by families on a national level (Smalley et al., 2014; U.S. Census Bureau, 2019). I used the NSCH to (1) determine the extent to which variability in PFCC exists within states vs. between states, (2) identify states with the highest and lowest amount of PFCC received among U.S. children/families, and (3) identify states with the highest and lowest amount of PFCC received among U.S. children/families CSHCN status and health care status.

Findings may be used to build evidence for states to focus on the training and use of PFCC in caring for pediatric age patients to increase the quality of care received in their state. State comparisons and data disaggregation provide state policymakers and public health professionals with specific information about what predictors are associated with the quality of care received by children, which can help to make informed decisions about resource allocation, policies, and programs. States with higher amounts of PFCC may be able to offer guidance to other state programs to aid in increasing the quality of care received by children in their state. This may also be true for states who have a higher delivery of PFCC to CSHCN and those with CLEH. Researchers can study health policies, insurance access and pricing, along with many other possible predictors of PFCC more closely for states with higher delivery of PFCC. Federal funders like the NIH and the CDC can use results to prioritize states with the greatest need for support in this area and guide the direction of funding for research. This may include creating programs and supporting research that focuses on within-state differences in the receipt of PFCC.

Methods

Primary Data Source and Population

This study used data from the 2018-2019 National Survey of Children's Health (NSCH) public use file. The NSCH is a cross-sectional self-report survey that is paper-based or completed online by a caregiver living in the home with the child of interest in order to understand the child's health and wellbeing. Survey results are often used to assess the national and state performance of child and family health. The National Center for Health Statistics at the Center for Disease Control conducts the NSCH annually with funding from the Maternal and Child Health Bureau. The NSCH is nationally representative of non-institutionalized children ages 0-17 living in the United States. The 2018-2019 NSCH dataset included 59,963 surveys and had a weighted response rate of 43.1% in 2018 and 42.4% in 2019. Residents of all fifty states and the District of Columbia were surveyed. Each state contributed approximately 1,176 survey responses (Data Resource Center for Child and Adolescent Health, 2020).

Outcome & Exclusions

The primary outcome of interest was the receipt of PFCC. A continuous composite variable for the PFCC was created using five components to measure how often the child's health care provider: (1) spent enough time with the child, (2) listened carefully, (3) was sensitive to the family's values and customs, (4) provided specific information to the patient/family, and (5) made the patient/family feel like a partner in the child's care. Responses to these five items were answered on a 4-point Likert scale ranging from "never" to "always". To examine the individual components of PFCC, items that were answered "usually" or "always" were considered to have received that specific component of PFCC. The initial sample size was 59,963, which was reduced to a final sample size of 38,803 responses after exclusion criteria were met. Exclusions included children/families who did not have an appointment with a healthcare provider in the last twelve months (n = 9,486), whose caregivers did not respond to all five PFCC items (n = 1,399), or who had any missing data for the included predictors (n = 10,275).

Statistical Analyses

All descriptive and statistical analyses were conducted using Stata 14 (StataCorp., 2015). A series of hierarchical multilevel logistic regression models (MLMs) were to assess the between-state approximate relative variation in the receipt of PFCC. The "mixed" function was used in Stata to create the MLMs with a continuous outcome for PFCC (Robson & Pevalin, 2015). Intercepts for all variables in the MLMs were allowed to vary in order to assess the approximate relative variation of PFCC between states. The variability in receipt of PFCC between and within states was measured using a continuous outcome of PFCC utilizing the "estat ic" function in Stata (Royston & Sauerbrei, 2008). The "regress" function in Stata was used for the non-MLM models to look at the differences between states in the receipt of PFCC by population with a continuous outcome (Dohoo et al., 2012).

The continuous composite variable for PFCC represents the number of components that were received by a respondent, ranging from zero to five.

The MLM analysis for the overall receipt of PFCC included six models, beginning with a null model. Null models were run for the overall receipt of PFCC, and for each population of interest (POC, CSHCN, and by health status). Null models assessed for the approximate relative variation in receipt of PFCC both within and between states. For the overall model, each model in the building process introduced a new category of variables as seen in Table 1. Models calculated the coefficient estimates, 95% confidence intervals (CI), and p-values for each variable to understand its association with the receipt of PFCC.

An additional regression model, using survey weights, was run and the “margins” function was used to produce marginal predictions for each state in the form of a predicted score (the average number of components received by children/families in a given state) (Mitchell, 2021; Williams, 2012). This score was used to examine the variation in receipt of PFCC by state. These scores were then visualized using a heatmap of the United States. Darker areas on the map represent receiving more components of PFCC and lighter areas represent receiving fewer components of PFCC. The five states with the most success and five states with the greatest challenges in delivering PFCC are compared in the discussion section. Similar methods were used for two datasets that were created from the final sample after exclusions. One data set only included CSHN and the other only included CLEH. These datasets were used to explore how PFCC differed for those populations by state. The overall final model was additionally assessed for the normality of residuals using a histogram and the Shapiro-Wilk test, the homoscedasticity of errors using a residuals vs. fitted plot, and outliers using Cook’s distance (<1) (Shapiro & Wilk, 1965; Cook, 1977; Kim & Storer, 1996).

Table 1

Hierarchical model building overall model

Model No.	Model Name	Variables Included
0	Null Model	Does not include any predictor variables. Assesses the approximate relative variation in receipt of PFCC
1	Child-Level Demographic Model	Sex of the child (female, male), age of the child in years (0-17), child nativity (born in the United States, born outside of the United States), insurance type (public health insurance only, private health insurance only, public and private insurance, currently uninsured), child race/ethnicity (Hispanic, and non-Hispanic: White, Black, Asian, American Indian or Alaska Native, Native Hawaiian and Other Pacific Islander, Multi-Race, Other)
2	Child-Level Needs Model	All above variables. Also includes: special health care status (SHCN, non-SHCN), and child health status (fair or poor, good, excellent or very good)
3	Child-Level Care Model	All above variables. Also includes: personal nurse or doctor (have at least one PDN, do not have a personal doctor or nurse), and place for usual sick care (doctor's office, hospital emergency room, hospital outpatient department, clinic or health center, retail store clinic or 'minute clinic', school, some other place)
4	Child-Level Household Model	All above variables. Also includes: household language (English, non-English), neighborhood safety (definitely agree, somewhat agree, somewhat/definitely disagree), school safety (definitely agree, somewhat agree, somewhat or definitely disagree, child age 0-5 years), family structure (two parents currently married, two parents not currently married, single parent, grandparent, other relation), and federal poverty level (FPL) (0-99%, 100-199%, 200-399%, 400% or above)
5	Overall Model/Child-Level Caregiver Model	All above variables. Also includes: caregiver sex (female, male), mother health status (physical & mental health both excellent/very good, one or both of physical & mental health are not excellent/very good, no mother reported in the household), father health status (physical & mental health both excellent/very good, one or both of physical & mental health are not excellent/very good, no father reported in the household), the highest level of education among reported adults in the household (less than high school, high school degree or GED, some college or technical school, college degree or higher), and parent nativity (parent(s) born in US, any parent born outside US, other)

6	CSHCN Model	All variables from overall model except CSHCN status. Only children with special health care needs were included.
7	Health Status Model	All variables from overall model except child health status. Only children with good, and fair/poor health status were included.

Results

Model Fit

Combined residual variance estimates between the null (.56) and final (.52) PFCC models showed a 6% reduction after adjusting for covariates. The Akaike information criteria (AIC) and Bayesian information criteria (BIC) were used to assess model fit. After a series of hierarchical models, the final PFCC model's AIC (85165.36) and BIC (85576.54) showed a reduction from the null model's AIC (87429.01) and BIC (87454.71); this indicated model improvement. The need for multilevel modeling was not statistically justified by the intraclass correlation (ICC) of the PFCC model (.0022). Despite a low ICC, the ecological nature of the health system supports the use of multilevel modeling for the exploratory nature of this study and to examine between vs. within state differences.

Level 1 Results

Estimates produced by the multilevel mixed-effects linear regression included results at two levels, the child and the state. Child-level variables also reflect the family and neighborhood and can be subcategorized into demographic characteristics, health needs, health care, household characteristics, and caregiver characteristics. Each of these subcategories produced significant findings at the 0.05 confidence level (Table 2). As seen in Table 2, after controlling for covariates, those who received greater amounts of PFCC were older children, without a special health care need, in excellent health, insured, sought sick care at a doctor's office, had a personal doctor or nurse, had caregiver’s who definitely agreed that their schools and neighborhoods were safe, lived in households with a FPL of 400% or higher, had mother’s without mental or physical health conditions, and did not have parents who were unmarried. Due to the aims of this study to focus on the state in which a child/family lives, many level one variables will not be explored further; however, they did yield interesting results for future review.

People of Color

The unadjusted model for race/ethnicity showed significant disparities for those who identified as Hispanic (-.10, 95% CI [-.13, .08]), Black (-.12, 95% CI [-.15, -.08]), American Indian or Alaskan Native (-.22, 95% CI [-.33, -.10]), and Multi-racial (-.04, 95% CI [-.08, -.05]). After covariates were included, no significant relationship was found between PFCC and any race or ethnicity. This suggests that the predictors included explain the disparities in the unadjusted model. Health status, insurance, school and neighborhood safety, and FPL accounted for the biggest difference between the unadjusted and adjusted models for those who identified as Black. For those who identified as Hispanic, school and neighborhood safety, family structure, and FPL accounted for differences from the unadjusted to the adjusted model. For those who identified as Multiracial, insurance, mother’s health status, and parent nativity accounted for differences from the unadjusted to the adjusted model. Lastly, for those who identified as American Indian or Alaskan Native having a personal nurse or doctor, school and neighborhood safety, and FPL accounted for differences from the unadjusted to the adjusted model.

Table 2

Coefficient estimates for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Coef. Est.	SE	p value	LL CI	UL CI
Sex of Child					
Male	0.02	0.01	0.03	0.00	0.03
Female	Reference				
Child Race/Ethnicity					
White, non-Hispanic	Reference				
Hispanic	-0.02	0.01	0.17	-0.05	0.01
Black, non-Hispanic	0.00	0.02	0.86	-0.04	0.03
Asian, non-Hispanic	-0.02	0.02	0.27	-0.07	0.02
American Indian or Alaska Native Non-Hispanic	-0.12	0.06	0.03	-0.23	-0.01
Native Hawaiian and Other Pacific Islander Non-Hispanic	-0.08	0.10	0.44	-0.27	0.12
Multi-Race Non-Hispanic	0.00	0.02	0.76	-0.03	0.03
Other Non-Hispanic	0.09	0.07	0.17	-0.04	0.23
Born in USA					
Born in US	Reference				
Born outside of US	0.06	0.02	0.02	0.01	0.11
Child Age	0.03	0.01	0.00	0.02	0.04
Insurance Type					
Private health insurance only	Reference				
Public health insurance only	-0.01	0.01	0.56	-0.03	0.02
Public and private insurance	-0.05	0.02	0.03	-0.09	-0.01
Currently uninsured	-0.12	0.02	0.00	-0.17	-0.08
Special Health Care Status					
Non-SHCN	Reference				
SHCN	-0.06	0.01	0.00	-0.07	-0.04
Child Health Status					
Excellent or very good	Reference				
Good	-0.14	0.02	0.00	-0.18	-0.11
Fair or Poor	-0.30	0.03	0.00	-0.37	-0.24
Place for Usual Sick Care					
Doctor's Office	Reference				
Hospital Emergency Room	-0.02	0.04	0.58	-0.11	0.06

Table 2

Coefficient estimates for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Coef. Est.	SE	p value	LL CI	UL CI
Hospital Outpatient Department	-0.15	0.05	0.00	-0.25	-0.05
Clinic or Health Center	-0.06	0.01	0.00	-0.08	-0.03
Retail Store Clinic or 'Minute Clinic'	-0.17	0.04	0.00	-0.24	-0.10
School (Nurse's Office, Athletic Trainer's Office)	-0.20	0.06	0.00	-0.33	-0.08
Some other place	-0.26	0.06	0.00	-0.37	-0.15
Personal Nurse or Doctor					
Have at least one PDN	Reference				
Do not have a personal doctor or nurse	-0.18	0.01	0.00	-0.20	-0.16
Household Language					
English	Reference				
Non-English	-0.05	0.02	0.02	-0.10	-0.01
School Safety					
Definitely agree	Reference				
Somewhat agree	-0.12	0.01	0.00	-0.14	-0.09
Somewhat or definitely disagree	-0.45	0.03	0.00	-0.51	-0.40
Children age 0-5 years	0.01	0.01	0.36	-0.01	0.04
Neighborhood Safety					
Definitely agree	Reference				
Somewhat agree	-0.08	0.01	0.00	-0.09	-0.06
Somewhat or definitely disagree	-0.23	0.02	0.00	-0.28	-0.19
Family Structure					
Two parents, currently married	Reference				
Two parents, not currently married	-0.06	0.02	0.00	-0.09	-0.02
Single parent (mother or father)	-0.06	0.03	0.02	-0.12	-0.01
Grandparent Household	0.07	0.06	0.25	-0.05	0.18
Other relation	-0.03	0.06	0.60	-0.14	0.08
Federal Poverty					
0-99% FPL	-0.10	0.02	0.00	-0.13	-0.06
100%-199% FPL	-0.06	0.01	0.00	-0.08	-0.03
200%-399% FPL	-0.04	0.01	0.00	-0.05	-0.02
400% FPL or above	Reference				

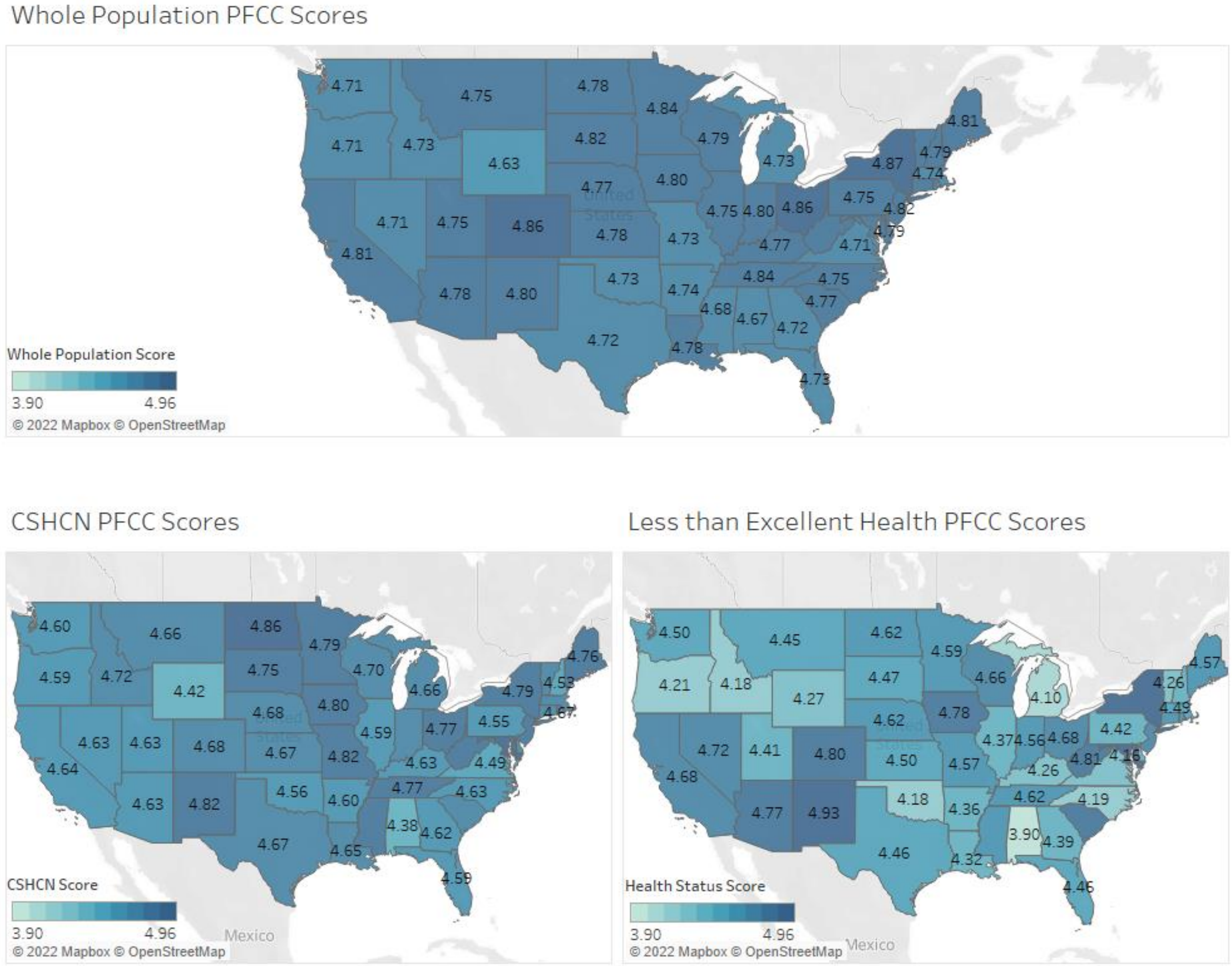
Table 2

Coefficient estimates for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Coef. Est.	SE	p value	LL CI	UL CI
Adult Education					
Less than high school	Reference				
High school degree or GED	0.05	0.04	0.16	-0.02	0.13
Some college or technical school	0.02	0.04	0.63	-0.05	0.09
College degree or higher	0.02	0.04	0.65	-0.06	0.09
Sex of Adult					
Male	Reference				
Female	0.00	0.01	0.58	-0.01	0.02
Mother Health Status					
Physical & mental health BOTH excellent/very good	Reference				
One or both of physical & mental health are NOT excellent/very good	-0.07	0.01	0.00	-0.08	-0.05
No mother reported in the household	-0.03	0.03	0.30	-0.09	0.03
Parent Nativity					
Parent(s) born in US	Reference				
Any parent born outside US	-0.04	0.01	0.00	-0.06	-0.01
Father Health Status					
Physical & mental health BOTH excellent/very good	Reference				
One or both of physical & mental health are NOT excellent/very good	-0.03	0.01	0.01	-0.04	-0.01
No father reported in the household	-0.01	0.03	0.76	-0.06	0.04

Figure 1

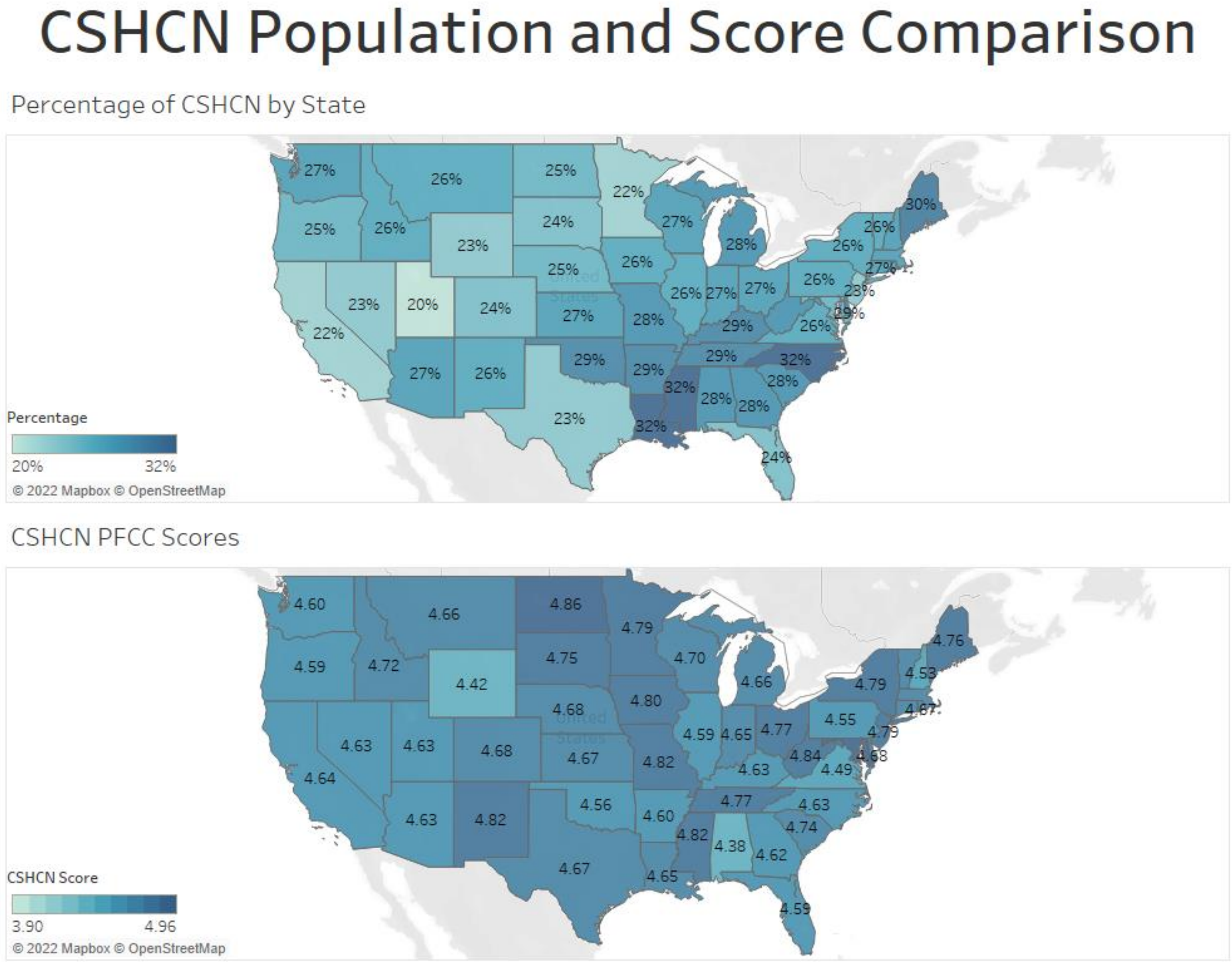
U.S. map of the average composite patient/family-centered care (PFCC) scores by state for the whole sample population of children 0-17, children with special health care needs, and children with less *than excellent health, 2018-2019 National Survey of Children's Health.*



Note: At the top, U.S. map of the average composite patient/family-centered care (PFCC) score by state for the whole sample population of children 0-17. Below from left to right are U.S. maps of the average composite PFCC score by CSHCN status and child health status. Scores represent the average number of components of PFCC that a child/family receives. This number could range from 0 to 5. The scores shown above range from 3.90 to 4.96 to reflect the average ranges for each state in the sample population.

Figure 2

U.S. map of the percentage of CSHCN by state as compared to the average composite patient/family-centered care (PFCC) score by state, 2018-2019 National Survey of Children's Health.



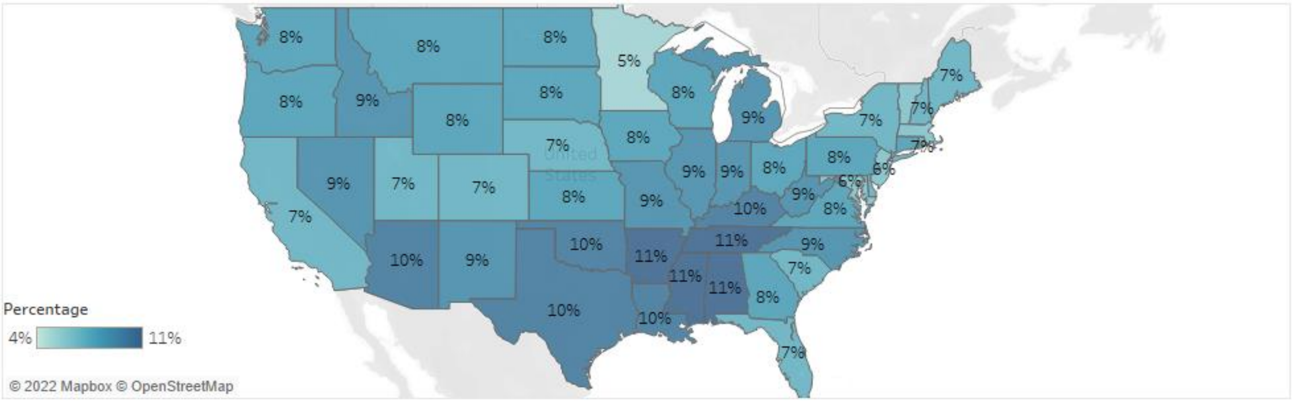
Note: At the top, U.S. map of the percentage of CSHCN by state ranging from 20% to 32%. At the bottom, the average composite patient/family-centered care (PFCC) score by state. Scores represent the average number of components of PFCC that a child/family receives. This number could range from 0 to 5. The scores shown above range from 3.90 to 4.96 to reflect the average ranges for each state in the sample population.

Figure 3

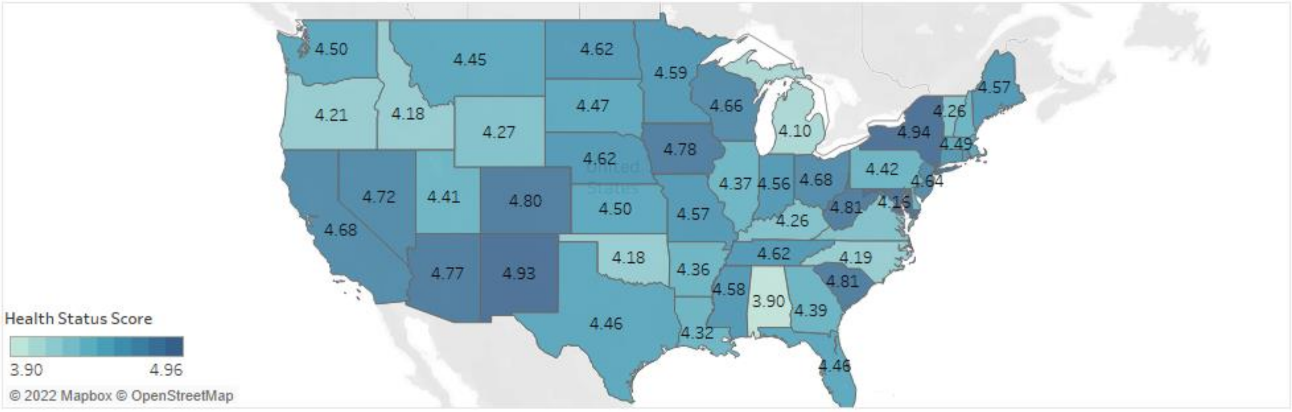
U.S. map of the percentage of CLEH by state as compared to the average composite patient/family-centered care (PFCC) score by state, 2018-2019 National Survey of Children's Health.

CLEH Population and Score Comparison

Percentage of CLEH by State



Less than Excellent Health PFCC Scores



Note: At the top, the U.S. map of the percentage of CLEH by state ranges from 4% to 11%. At the bottom, the average composite patient/family-centered care (PFCC) score by state. Scores represent the average number of components of PFCC that a child/family receives. This number could range from 0 to 5. The scores shown above range from 3.90 to 4.96 to reflect the average ranges for each state in the sample population.

State Variability of PFCC by CSHCN Status and Health Status

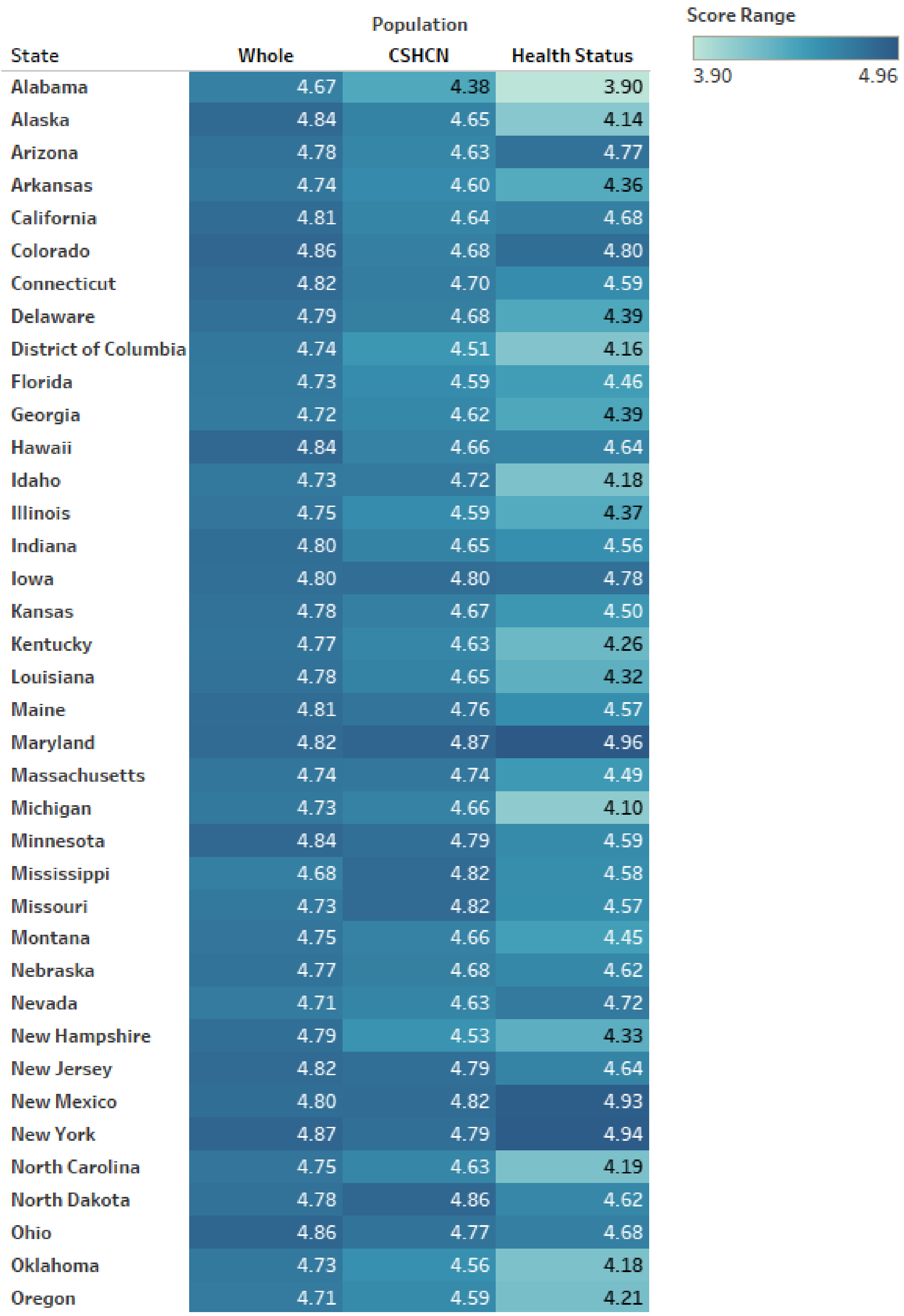
The current study found PFCC negatively associated with special health care need status (-0.06, 95% CI [-0.07, -0.04]) and child health status (good, -0.14, 95% CI [-0.18, -0.11]) (fair/poor, -0.30, 95% CI [-.037, -0.24]). Null model ICCs indicated that the receipt of PFCC for CSHCN (.0043) and CLEH (.0095) was mostly explained by within state differences; however, between state differences were slightly greater for these populations than for the full sample population, particularly for health status.

The state variability in receipt of PFCC by CSHCN status and health status can be seen in Figures 2, 3, and 4. These figures highlight differences across states according to their ability to deliver PFCC to children/families for these populations. Each score represents the average number of PFCC components that were received by children/families in that state. Lower scores could be seen in Alabama (4.38), Wyoming (4.42), Virginia (4.48), District of Columbia (4.51), and New Hampshire (4.53). Alternatively, the following states had the highest scores for children/families with SHCNs: Maryland (4.87), North Dakota (4.86), West Virginia (4.84), Mississippi (4.82), and Missouri (4.82). The scores for CSHCN ranged from 4.38 - 4.87, which is a wider range than the full sample’s range (4.63 - 4.87).

Lower scores for CLEH could be seen in Alabama (3.90), Michigan (4.10), Alaska (4.16), the District of Columbia (4.16), and Idaho (4.18). Conversely, the following states had the highest scores for CLEH: Maryland (4.96), New York (4.94), New Mexico (4.96), West Virginia (4.82), and South Carolina (4.81). The scores for CLEH ranged from 3.86 - 4.95, which is the widest range when compared to CSHCN and the full sample. Figure 2 indicates that all states received at least three of the five components of PFCC. It is important to note that although the initial sample size was large, stratification by state reduced the sample size and limited the precision of the estimates for the outcome of PFCC. As seen in Figures 2 and 3, there does appear to be a small relationship between the percentage of CSHCN or CLEH in a state and the state’s score for PFCC for that population; however, results were not consistent throughout the country.

Figure 4

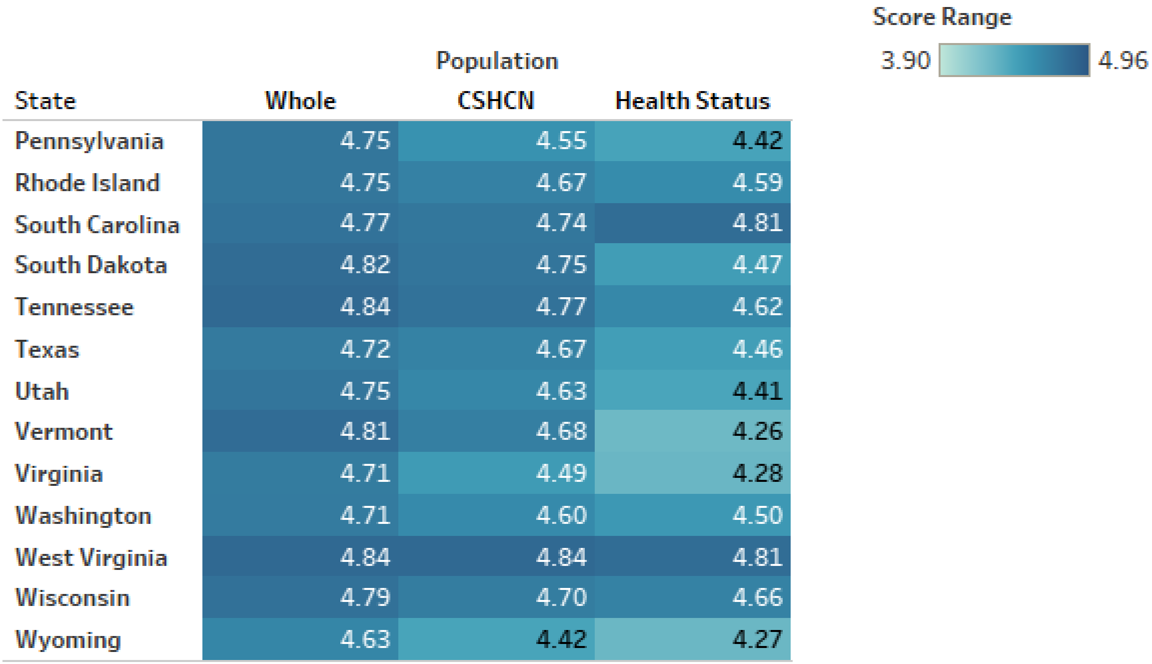
Average Composite Patient/Family-Centered Care Score by State for Children 0-17, 2018-2019 National Survey of Children's Health. Disaggregated by CSHCN Status and Child Health Status.



	Population		
State	Whole	CSHCN	Health Status
Alabama	4.67	4.38	3.90
Alaska	4.84	4.65	4.14
Arizona	4.78	4.63	4.77
Arkansas	4.74	4.60	4.36
California	4.81	4.64	4.68
Colorado	4.86	4.68	4.80
Connecticut	4.82	4.70	4.59
Delaware	4.79	4.68	4.39
District of Columbia	4.74	4.51	4.16
Florida	4.73	4.59	4.46
Georgia	4.72	4.62	4.39
Hawaii	4.84	4.66	4.64
Idaho	4.73	4.72	4.18
Illinois	4.75	4.59	4.37
Indiana	4.80	4.65	4.56
Iowa	4.80	4.80	4.78
Kansas	4.78	4.67	4.50
Kentucky	4.77	4.63	4.26
Louisiana	4.78	4.65	4.32
Maine	4.81	4.76	4.57
Maryland	4.82	4.87	4.96
Massachusetts	4.74	4.74	4.49
Michigan	4.73	4.66	4.10
Minnesota	4.84	4.79	4.59
Mississippi	4.68	4.82	4.58
Missouri	4.73	4.82	4.57
Montana	4.75	4.66	4.45
Nebraska	4.77	4.68	4.62
Nevada	4.71	4.63	4.72
New Hampshire	4.79	4.53	4.33
New Jersey	4.82	4.79	4.64
New Mexico	4.80	4.82	4.93
New York	4.87	4.79	4.94
North Carolina	4.75	4.63	4.19
North Dakota	4.78	4.86	4.62
Ohio	4.86	4.77	4.68
Oklahoma	4.73	4.56	4.18
Oregon	4.71	4.59	4.21

Figure 4 Continued

Average Composite Patient/Family-Centered Care Score by State for Children 0-17, 2018-2019 National Survey of Children's Health. Disaggregated by CSHCN Status and Child Health Status.



		Population	
State	Whole	CSHCN	Health Status
Pennsylvania	4.75	4.55	4.42
Rhode Island	4.75	4.67	4.59
South Carolina	4.77	4.74	4.81
South Dakota	4.82	4.75	4.47
Tennessee	4.84	4.77	4.62
Texas	4.72	4.67	4.46
Utah	4.75	4.63	4.41
Vermont	4.81	4.68	4.26
Virginia	4.71	4.49	4.28
Washington	4.71	4.60	4.50
West Virginia	4.84	4.84	4.81
Wisconsin	4.79	4.70	4.66
Wyoming	4.63	4.42	4.27

Overall Receipt of PFCC by State

The state variability in receipt of PFCC for the full sample population can be seen in Figure 2. This figure highlights differences among states according to their ability to deliver PFCC. Lower scores could be seen in Wyoming (4.63), Alabama (4.67), Mississippi (4.68), Virginia (4.71), and Nevada (4.71). In contrast, the highest-scoring states were New York (4.87), Ohio (4.86), Colorado (4.86), Minnesota (4.84), and Hawaii (4.84). Scores ranged from 4.63 - 4.87, which is the smallest range when compared to just CSHCN status or health status models.

Level 2 Results

In an unadjusted model of PFCC, the between states variance explained was 0.0022. This suggests within state differences explain the majority of the receipt of PFCC in this sample.

Discussion

This study used multilevel modeling, linear regression, and heat mapping to explore the receipt of PFCC for children in the US, with a focus on differences across states. It was conducted to provide researchers, funders, and states the ability to compare PFCC by state and to assist with funding allocation towards these efforts. Additionally, it will add to the literature to support future research and program development, help states understand their current ability to provide PFCC to children in their state, and identify possible states to partnerships. While further investigation is needed, this study serves as an initial inquiry.

This study had three aims, (1) determine the extent to which variability in PFCC exists within states vs. between states, (2) identify states with the highest and lowest amount of PFCC among U.S. children/families, and (3) identify states with the highest and lowest amount of PFCC among U.S. children/families by CSHCN status and health status. Some key takeaways emerged from this study's findings. First, many of the predictors that were included in the final PFCC model were significantly associated with the receipt of PFCC; however, they still only explained 6% of the variance. It is possible that many factors that contribute to the receipt of PFCC are either unknown, not included in the NSCH, or were not included in this study. Gaining insight into barriers for health systems and providers could be helpful to bridge this gap in understanding as well as continue research into the delivery of high-quality health care.

Second, the prevalence of PFCC for each state for the full sample was over 91%. While this is a high percentage, it does not include the voices of those who were not able to see a provider in the last 12 months, those who did not answer all of the PFCC component questions, those who had any missing data for the included predictors, or other measures of the quality of care received. More variation in the quality of care and greater disparities may be present in a study that takes a different design approach that can expand on quantitative data, include other measures of quality of care, and reach currently unheard voices. It is also possible that the lack of variation in the receipt of PFCC was due to the NSCH's insensitivity in measuring PFCC. The NSCH only included five items about PFCC. Survey items were non-specific and not easily measurable or specific. Future studies should utilize other measures of PFCC to avoid underrepresenting the receipt of PFCC and better understanding disparities.

Third, where a child/family lives is important. Consistent with other studies, the safety of the neighborhood and school make a difference in the receipt of PFCC. This may be related to or explained by unknown predictors in a way that is not yet fully understood and requires further investigation. For example, access to high-quality care not being readily available in areas that are considered unsafe. Additionally, there was some variation in the receipt of PFCC by state which provides insights to grantors, training programs, and supportive programs; however, state may be too large of a geographical unit for these results to be as meaningful as they could be. While this study's framework supported the use of MLM, there was little to no clustering at the state level. Future studies should include lower-level variables; for example, locality FIPS codes or zip codes.

A state's health policies, priorities, and programs are important to consider in the quality of care received. Similarly, each locality and local community also plays an important role for residents of the state. Some parts of a state are rural, medically underserved, or have protective factors that may be important to consider. These factors may explain why between-state differences were very small. There are several ways to better understand why most of the variation in receipt of PFCC was within the state. Additional levels for exploration could be added to the study that may include patients being nested within a provider's patients, within a health system, within a locality, within a state. The sample size may be too small to analyze the NSCH at these levels or these levels may not be available in the NSCH. Future studies should consider combining five years worth of data to open new possibilities in researching PFCC using the NSCH and utilizing datasets with these levels and variables available.

Fourth, some states appear to be consistently associated with lower quality of care, which is concerning (Azuine et al., 2015; Singh et al., 2009). Many of these lower-performing states are located in the southeastern region of the United States. This study found Alabama, Mississippi, Wyoming, Virginia, and Nevada among the lowest-performing states for PFCC for the full sample population, which was similar to findings by Azuine et al. (2015). To better understand the mechanisms behind these disparities and make meaningful change, public policies and programs need to be examined and compared between top-performing states and lower-performing states. For example, one similarity that was noticed was a possible relationship between the cost of insurance and the receipt of PFCC (Kaiser Family Foundation, 2020). States should form partnerships to help support and elevate one another in increasing the quality of care received in their state. Funders and grantors should prioritize states with the greatest need.

There did appear to be a relationship between the number of CSHCN and CLEH in a state and that state's score for the delivery of PFCC, as evidenced by figures 2 and 3; however, because this was not consistent throughout the country and because of the nature of this study, the conclusion can not be made that states with lower PFCC scores are due to the number of CSHCN and CLEH in a state. Some states with the highest percentages of these populations still had higher PFCC scores than other states. Environmental factors/laws, state policies, health system standards, and barriers to accessing insurance in these states might explain the high percentages of these populations in these states. These findings are cause for further investigation into state differences in the quality of care delivered by state and also mechanisms that contribute to child health by state. It is important to note that the NSCH oversampled CSHCN. While variations by state were significant, most of the variation in the receipt of PFCC happened within a state. It is possible that the overall state averages mask greater differences between states; however, within state findings in combination with significant results for neighborhood safety and school safety, point to further exploration. Lower geographic levels that include the localities, health systems, and neighborhoods should be studied further to better understand contextual factors for these variances within the state. Finding or creating data that includes these levels is important. Most studies focus on child/family-level characteristics because of the readily available nature of secondary data like the NSCH; however, we must challenge ourselves to gather other types of data that will help to create a fuller picture of the problem. Individual characteristics likely account for less of the receipt of high-quality care than other influences. It is important to acknowledge the difficulty in gaining access to health providers to study or health systems who are willing to work with researchers about their own performance (Institute of Medicine (US) Forum on Drug Discovery, 2010).

Fifth, results for CSHCN were highly significant ($p < .001$) in both the unadjusted analysis and the adjusted analyses of the final model. There was only a small reduction in the degree of PFCC disparity for CSHCN when adjustments were made for other predictors. This indicates that the predictors included in the final model did not explain much of the variability in receipt of PFCC for CSHCN. Similar results were found for CLEH; however, reductions in the disparities for this population from the unadjusted model to the adjusted model were reduced by almost half. This suggests that while the other included predictors do not fully explain the receipt of PFCC for CLEH, they do help explain some of the barriers for this population, including many predictors related to income. These results were not surprising and consistent with the literature which found disparities in receiving high-quality care for these two populations (Brannon et al., 2021; Martin et al., 2013; Montes & Halterman, 2011). Researchers should continue exploring challenges and barriers for these two vulnerable populations to better understand the challenges to receiving PFCC. This could include disaggregating results by type of special health care need and cause of poor health, because different health concerns may require special attention or experience greater disparities than others. For example, support for mental health needs (Campbell et al., 2007).

Additionally, score ranges for the full sample population, CSHCN, and by health status were very similar; however, health status had the greatest range and appeared to need the most support. Alabama was one of the lowest-performing states for all three populations but other lower-performing states did not overlap for all three populations. There was more overlap in the highest and lowest performing states for CSHCN status and health status, which is logical. Alabama and Alaska were among the five lowest-performing states, and Maryland and West Virginia were among the top five highest-performing states for CSHCN and CLEH. Other top and bottom-performing states varied between the two populations. Some states may specialize in treating specific special healthcare needs or have large high-quality medical centers. Further investigation into these differences is needed; however, overall, all populations received at least three components of PFCC, and most received four.

Lastly, when predictors were included in the final PFCC adjusted model, the outcome was not significant for any race/ethnicity. This suggests that the predictors included explain the disparities in the unadjusted model. While this is consistent with some studies (Bleser et al., 2017), it contradicts others (Azuine et al., 2015; Smalley et al., 2014; Zajicek-Faber et al., 2017). It is possible that with a different sample, categorizing race/ethnicity similarly, or having more clearly defined and quantifiable outcomes for PFCC, the results may have been significant. Some studies have suggested that healthcare for POC varies by state. Due to the current study's findings being non-significant and small sample sizes after stratification, receipt of PFCC was not further stratified by race/ethnicity, which limits the ability of this study to explore between state differences in the receipt of PFCC for POC.

Another important factor in the study of racial/ethnic disparities is the ability to consider possible influences of discrimination, which may vary by region (Almeida et al., 2022; Volpe et al., 2021; Kim et al., 2016). Discrimination may be reflected in the policies of the state, impact the provider's ability to provide culturally competent care, and have other unknown impacts on the health of people of color (POC) (Almeida et al., 2016; Brunett & Shingles, 2018; Zghal et al., 2021). Due to the variations in health policy and the possible influence of racism and discrimination by state/region, it is vital to consider patient location when researching racial/ethnic health disparities (Almeida et al., 2016; Volpe et al., 2021; Zikafoose, 2012; Kim et al., 2016). No predictors of discrimination are included in the NSCH and thus were unable to be studied. Future PFCC studies should explore racism and discrimination when possible and consider using data that also includes questions about discrimination to address another possible barrier for POC in receiving high-quality care. Alternatively, suggestions to the NSCH could be made for the addition of questions about discrimination that are similar to survey questions included on the Pregnancy Risk Assessment Monitoring System (PRAMS) survey (Almeida et al., 2022).

Limitations and Future Directions

It is important to note this study's limitations that have not already been mentioned. First, each of the components of PFCC ask about constructs that are subjective and answered on a Likert scale. Responses may vary by participant, particularly with what is considered never, sometimes, often, and always because it was not quantified. Second, race/ethnicity was a predictor of interest; however, the NSCH only includes the child’s race/ethnicity and not the caregiver’s. Caregivers are likely to interact with providers more than the child and results could differ from the current study if their race/ethnicity was included. Third, there were some important predictors and additional levels that were not studied. For example, the number of providers per child by state, health systems, cost of health care in each state, local communities and health programs, state policies, and sub-state level variations (locality, health system, etc). All of these areas could provide valuable insights and should be included in future studies of the quality of care received. Additional limitations stem from the nature of a cross-sectional survey, which is limited to the study of associations and does not allow for drawing causal conclusions from study results. Experimental studies and other data sources in this area should be used to further validate this study’s findings and resolve limitations. Further, utilizing a mixed-methods approach that includes qualitative data could help unpack answers to quantitative surveys of patients, families, and providers. Non-random error is also a limitation of cross-sectional surveys. The NSCH took many steps to prevent non-random error by randomly selecting participants, testing item questions, assuring confidentiality to respondents, etc; however, it may still be present (Data Resource Center for Child and Adolescent Health, 2011; United States Census Bureau, 2019). Lastly, no survey weights were included in the MLMs in this study to allow for exploring the use of a multilevel model; however, many of the survey items used for weighting were included as predictors.

Additionally, Carle 2009, found that when comparing unweighted and weighted analyses using similar methods, there were only small differences that did not impact result conclusions.

Conclusions

This study sought to explore how much of the variance in the receipt of PFCC is due to state differences for children living in the United States. Special attention was given to the state's ability to deliver PFCC to CSHCN, CLEH, and POC. This is the first study to explore these aims while utilizing multilevel modeling to control for contextual factors and child-level characteristics. While this approach attempted to methodologically strengthen the study of PFCC using the NSCH, it only explained 6% of the receipt of PFCC. The greatest variation in receipt of PFCC was explained by within-state differences as opposed to between states. This was true for the whole sample, CSHCN, and by health status. The receipt of PFCC did vary by state for all populations but was the most notable for CLEH.

This study's limitations point to the need for further investigation. Variances and disparities in the receipt of PFCC are still present across states after adjusting for individual characteristics for CSHCN, CLEH, the uninsured, and those with low FPLs. This is concerning for federal and state policies/programs that are tasked with increasing the health and well-being of children. Future research should study health policy differences by state, the number of providers per child, and other state contextual factors not included in this study. Geographic regions should be analyzed at a more localized level that may include localities and health systems. Future research should examine states that were associated with higher amounts of PFCC to understand protective factors for high levels of quality health care. Funders and training programs can focus on supporting providers and health systems in lower-performing states and encourage them to work with researchers to better study

PFCC. Partnerships can be facilitated between higher and lower performing states to encourage collaboration and learning to increase PFCC.

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Appendix A

Family-Centered Care Questions from the National Survey of Children's Health (NSCH)

Family-Centered Care				
[*Only answer questions D4-D12 if child had a healthcare visit in the past 12 months*] DURING THE PAST 12 MONTHS, how often did this child's doctors or other health care providers:				
Spend enough time with this child?	(1) Always	(2) Usually	(3) Sometimes	(4) Never
Listen carefully to you?	(1) Always	(2) Usually	(3) Sometimes	(4) Never
Show sensitivity to your family's values and customs?	(1) Always	(2) Usually	(3) Sometimes	(4) Never
Provide the specific information you needed concerning this child?	(1) Always	(2) Usually	(3) Sometimes	(4) Never
Help you feel like a pattern in this child's care?	(1) Always	(2) Usually	(3) Sometimes	(4) Never

Appendix B

Proposed Journals

Choice	**Journal**	**Journal Focus**
1	Patient Education and Counseling	Explores educational, counseling, and communication models in healthcare. Fundamental and applied research. Promotes the study of organization issues with delivery of patient education, counseling, provider training, and communication between providers and patients
2	Maternal Child Health Journal	Maternal and Child Health practice, policy, and research. Explores epidemiology, geography, health status, policy, and advocacy.
3	Journal of Child and Family Studies	Behavioral health and well-being of children, adolescents, and families. Community context that influences well-being. Looks for practical application for providers, implementers, and policymakers.

Appendix C

Model building for study 1

Model 1

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
Sex of Child					
Male	1.10	0.09	0.26	0.93	1.29
Female	Reference				
Born in USA					
Born in US	Reference				
Born outside of US	0.80	0.13	0.17	0.58	1.10
Child Age	0.93	0.03	0.06	0.87	1.00
Insurance Type					
Private health insurance only	Reference				
Public health insurance only	0.56	0.07	0.00	0.44	0.71
Public and private insurance	0.51	0.06	0.00	0.41	0.65
Currently uninsured	0.50	0.06	0.00	0.39	0.64

Model 2

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
Sex of Child					
Male	1.08	0.09	0.36	0.91	1.28
Female	Reference				
Born in USA					
Born in US	Reference				
Born outside of US	0.79	0.13	0.17	0.57	1.11
Child Age	0.98	0.04	0.59	0.91	1.06
Insurance Type					
Private health insurance only	Reference				
Public health insurance only	0.62	0.08	0.00	0.49	0.79
Public and private insurance	0.60	0.07	0.00	0.48	0.74
Currently uninsured	0.52	0.06	0.00	0.41	0.65
Special Health Care Status					

Model 2 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
Non-SHCN	Reference				
SHCN	0.86	0.05	0.01	0.77	0.96
Child Health Status					
Excellent or very good	Reference				
Good	0.50	0.04	0.00	0.43	0.58
Fair or Poor	0.37	0.06	0.00	0.27	0.52

Model 3

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
Sex of Child					
Male	1.09	0.10	0.34	0.91	1.30
Female	Reference				
Born in USA					
Born in US	Reference				
Born outside of US	0.84	0.14	0.30	0.60	1.17
Child Age	1.00	0.04	0.99	0.93	1.08
Insurance Type					
Private health insurance only	Reference				
Public health insurance only	0.71	0.10	0.02	0.53	0.94
Public and private insurance	0.66	0.07	0.00	0.53	0.81
Currently uninsured	0.61	0.07	0.00	0.48	0.77
Special Health Care Status					
Non-SHCN	Reference				
SHCN	0.79	0.05	0.00	0.70	0.88
Child Health Status					
Excellent or very good	Reference				
Good	0.51	0.04	0.00	0.45	0.59
Fair or Poor	0.38	0.07	0.00	0.26	0.56
Place for Usual Sick Care					
Doctor's Office	Reference				
Hospital Emergency Room	0.67	0.17	0.11	0.41	1.09

Model 3 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
Hospital Outpatient Department	0.34	0.14	0.01	0.15	0.78
Clinic or Health Center	0.64	0.09	0.00	0.49	0.83
Retail Store Clinic or 'Minute Clinic'	0.50	0.18	0.06	0.25	1.01
School (Nurse's Office, Athletic Trainer's Office)	1.43	0.74	0.49	0.52	3.97
Some other place	0.60	0.26	0.25	0.26	1.42
Personal Nurse or Doctor					
Have at least one PDN	Reference				
Do not have a personal doctor or nurse	0.45	0.03	0.00	0.40	0.51

Model 4

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
Sex of Child					
Male	1.10	0.09	0.26	0.93	1.30
Female	Reference				
Born in USA					
Born in US	Reference				
Born outside of US	0.96	0.19	0.84	0.66	1.41
Child Age	1.11	0.05	0.03	1.01	1.22
Insurance Type					
Private health insurance only	Reference				
Public health insurance only	1.00	0.15	0.99	0.74	1.35
Public and private insurance	0.84	0.10	0.16	0.66	1.07
Currently uninsured	0.76	0.11	0.05	0.58	1.00
Special Health Care Status					
Non-SHCN	Reference				
SHCN	0.79	0.05	0.00	0.70	0.89
Child Health Status					
Excellent or very good	Reference				
Good	0.61	0.05	0.00	0.53	0.70
Fair or Poor	0.48	0.08	0.00	0.34	0.66

Model 4 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
Place for Usual Sick Care					
Doctor's Office	Reference				
Hospital Emergency Room	0.80	0.23	0.44	0.46	1.41
Hospital Outpatient Department	0.40	0.18	0.04	0.17	0.95
Clinic or Health Center	0.71	0.10	0.02	0.53	0.94
Retail Store Clinic or 'Minute Clinic'	0.41	0.16	0.02	0.20	0.86
School (Nurse's Office, Athletic Trainer's Office)	1.32	0.69	0.59	0.48	3.65
Some other place	0.75	0.35	0.54	0.30	1.86
Personal Nurse or Doctor					
Have at least one PDN	Reference				
Do not have a personal doctor or nurse	0.47	0.03	0.00	0.42	0.52
Household Language					
English	Reference				
Non-English	0.63	0.07	0.00	0.51	0.79
School Safety					
Definitely agree	Reference				
Somewhat agree	0.53	0.04	0.00	0.45	0.62
Somewhat or definitely disagree	0.41	0.07	0.00	0.29	0.58
Children age 0-5 years	0.98	0.09	0.81	0.81	1.17
Neighborhood Safety					
Definitely agree	Reference				
Somewhat agree	0.60	0.05	0.00	0.50	0.71
Somewhat or definitely disagree	0.45	0.06	0.00	0.35	0.57
Family Structure					
Two parents, currently married	Reference				
Two parents, not currently married	0.84	0.12	0.24	0.63	1.12
Single parent (mother or father)	0.76	0.07	0.00	0.64	0.92
Grandparent Household	1.42	0.30	0.10	0.93	2.16
Other relation	0.92	0.34	0.83	0.45	1.91
Federal Poverty					
0-99% FPL	0.74	0.07	0.00	0.62	0.89

Model 4 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
100%-199% FPL	0.75	0.08	0.01	0.61	0.92
200%-399% FPL	0.75	0.06	0.00	0.64	0.88
400% FPL or above	Reference				
State					
Alabama	0.72	0.03	0.00	0.66	0.79
Alaska	1.39	0.05	0.00	1.29	1.50
Arizona	0.85	0.05	0.00	0.76	0.94
Arkansas	0.99	0.05	0.84	0.90	1.09
California	1.03	0.04	0.52	0.95	1.11
Colorado	1.56	0.05	0.00	1.47	1.67
Connecticut	1.64	0.07	0.00	1.51	1.79
Delaware	1.10	0.05	0.03	1.01	1.19
District of Columbia	0.96	0.04	0.26	0.88	1.03
Florida	0.96	0.06	0.52	0.85	1.08
Georgia	0.89	0.04	0.01	0.82	0.98
Hawaii	1.43	0.03	0.00	1.37	1.49
Idaho	0.96	0.03	0.24	0.90	1.03
Illinois	1.09	0.04	0.02	1.01	1.17
Indiana	1.03	0.03	0.41	0.96	1.10
Iowa	1.22	0.04	0.00	1.14	1.31
Kansas	1.19	0.04	0.00	1.11	1.28
Kentucky	1.12	0.04	0.00	1.04	1.20
Louisiana	0.99	0.07	0.85	0.87	1.13
Maine	1.24	0.04	0.00	1.16	1.32
Maryland	1.12	0.04	0.00	1.03	1.20
Massachusetts	1.14	0.04	0.00	1.07	1.22
Michigan	0.87	0.03	0.00	0.81	0.93
Minnesota	1.76	0.04	0.00	1.67	1.85
Mississippi	0.76	0.04	0.00	0.69	0.83
Missouri	0.99	0.03	0.65	0.94	1.04
Montana	0.99	0.02	0.83	0.95	1.04
Nebraska	1.06	0.03	0.06	1.00	1.11
Nevada	0.94	0.04	0.15	0.87	1.02
New Hampshire	1.21	0.03	0.00	1.14	1.27
New Jersey	1.32	0.05	0.00	1.22	1.43
New Mexico	1.08	0.05	0.11	0.98	1.20
New York	1.53	0.08	0.00	1.39	1.69

Model 4 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
North Carolina	0.90	0.04	0.02	0.83	0.98
North Dakota	1.14	0.04	0.00	1.07	1.21
Ohio	1.62	0.06	0.00	1.51	1.73
Oklahoma	1.08	0.04	0.05	1.00	1.16
Oregon	0.83	0.03	0.00	0.77	0.89
Pennsylvania	0.89	0.05	0.05	0.80	1.00
Rhode Island	0.95	0.03	0.13	0.88	1.02
South Carolina	0.95	0.05	0.34	0.85	1.06
South Dakota	1.24	0.02	0.00	1.20	1.28
Tennessee	1.46	0.07	0.00	1.34	1.60
Texas	0.86	0.03	0.00	0.79	0.93
Utah	Reference				
Vermont	1.31	0.09	0.00	1.15	1.49
Virginia	0.82	0.02	0.00	0.78	0.86
Washington	0.85	0.03	0.00	0.80	0.91
West Virginia	1.27	0.06	0.00	1.16	1.38
Wisconsin	1.01	0.03	0.84	0.96	1.06
Wyoming	0.62	0.01	0.00	0.61	0.64

Model 5

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
Sex of Child					
Male	1.10	0.09	0.25	0.93	1.31
Female	Reference				
Born in USA					
Born in US	Reference				
Born outside of US	1.01	0.19	0.97	0.69	1.46
Child Age	1.12	0.05	0.02	1.02	1.23
Insurance Type					
Private health insurance only	Reference				
Public health insurance only	1.04	0.18	0.83	0.74	1.46
Public and private insurance	0.85	0.11	0.21	0.67	1.09
Currently uninsured	0.75	0.09	0.02	0.59	0.96
Special Health Care Status					
Non-SHCN	Reference				

Model 5 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
SHCN	0.79	0.05	0.00	0.70	0.89
Child Health Status					
Excellent or very good	Reference				
Good	0.67	0.05	0.00	0.58	0.77
Fair or Poor	0.51	0.09	0.00	0.37	0.71
Place for Usual Sick Care					
Doctor's Office	Reference				
Hospital Emergency Room	0.85	0.24	0.55	0.49	1.47
Hospital Outpatient Department	0.40	0.18	0.04	0.16	0.97
Clinic or Health Center	0.73	0.10	0.03	0.56	0.96
Retail Store Clinic or 'Minute Clinic'	0.42	0.15	0.02	0.20	0.86
School (Nurse's Office, Athletic Trainer's Office)	1.38	0.72	0.54	0.49	3.86
Some other place	0.74	0.35	0.53	0.30	1.86
Personal Nurse or Doctor					
Have at least one PDN	Reference				
Do not have a personal doctor or nurse	0.47	0.03	0.00	0.42	0.52
Household Language					
English	Reference				
Non-English	0.74	0.10	0.02	0.58	0.96
School Safety					
Definitely agree	Reference				
Somewhat agree	0.54	0.05	0.00	0.45	0.65
Somewhat or definitely disagree	0.42	0.07	0.00	0.30	0.58
Children age 0-5 years	0.98	0.09	0.86	0.82	1.18
Neighborhood Safety					
Definitely agree	Reference				
Somewhat agree	0.63	0.05	0.00	0.53	0.74
Somewhat or definitely disagree	0.48	0.06	0.00	0.37	0.62
Family Structure					
Two parents, currently married	Reference				
Two parents, not currently married	0.84	0.13	0.26	0.63	1.13
Single parent (mother or father)	0.57	0.18	0.07	0.31	1.05
Grandparent Household	1.29	0.86	0.71	0.35	4.73
Other relation	0.75	0.52	0.68	0.20	2.90
Federal Poverty					
0-99% FPL	0.74	0.08	0.01	0.59	0.92
100%-199% FPL	0.75	0.10	0.03	0.59	0.97

Model 5 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
200%-399% FPL	0.76	0.06	0.00	0.65	0.88
400% FPL or above	Reference				
State					
Alabama	0.71	0.03	0.00	0.66	0.77
Alaska	1.42	0.06	0.00	1.31	1.53
Arizona	0.88	0.04	0.01	0.80	0.96
Arkansas	0.99	0.05	0.85	0.91	1.09
California	1.05	0.03	0.13	0.99	1.12
Colorado	1.61	0.05	0.00	1.51	1.72
Connecticut	1.71	0.07	0.00	1.57	1.85
Delaware	1.12	0.04	0.01	1.03	1.21
District of Columbia	0.93	0.03	0.03	0.87	0.99
Florida	0.98	0.06	0.69	0.87	1.09
Georgia	0.90	0.04	0.01	0.83	0.97
Hawaii	1.52	0.04	0.00	1.44	1.60
Idaho	0.97	0.04	0.39	0.90	1.04
Illinois	1.11	0.03	0.00	1.05	1.18
Indiana	1.05	0.04	0.18	0.98	1.12
Iowa	1.21	0.04	0.00	1.14	1.30
Kansas	1.19	0.05	0.00	1.10	1.29
Kentucky	1.13	0.04	0.00	1.05	1.22
Louisiana	0.96	0.06	0.53	0.85	1.09
Maine	1.25	0.05	0.00	1.15	1.36
Maryland	1.15	0.04	0.00	1.08	1.24
Massachusetts	1.15	0.04	0.00	1.07	1.24
Michigan	0.89	0.03	0.00	0.83	0.95
Minnesota	1.77	0.04	0.00	1.69	1.86
Mississippi	0.74	0.03	0.00	0.68	0.80
Missouri	0.98	0.03	0.46	0.92	1.04
Montana	1.01	0.03	0.83	0.94	1.07
Nebraska	1.06	0.03	0.04	1.00	1.12
Nevada	0.99	0.03	0.71	0.93	1.05
New Hampshire	1.20	0.04	0.00	1.13	1.27
New Jersey	1.39	0.05	0.00	1.29	1.50
New Mexico	1.10	0.05	0.07	0.99	1.21
New York	1.62	0.07	0.00	1.50	1.76
North Carolina	0.92	0.04	0.05	0.85	1.00
North Dakota	1.14	0.04	0.00	1.06	1.22
Ohio	1.63	0.06	0.00	1.51	1.76
Oklahoma	1.07	0.04	0.07	1.00	1.15
Oregon	0.88	0.04	0.00	0.80	0.96
Pennsylvania	0.90	0.05	0.06	0.81	1.00
Rhode Island	0.97	0.03	0.42	0.91	1.04
South Carolina	0.93	0.04	0.13	0.85	1.02
South Dakota	1.21	0.02	0.00	1.18	1.24

Model 5 Continued

Adjusted Odds Ratios for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Adjusted Odds Ratio	SE	p value	LL CI	UL CI
Tennessee	1.48	0.08	0.00	1.33	1.64
Texas	0.86	0.03	0.00	0.81	0.92
Utah	Reference				
Vermont	1.31	0.09	0.00	1.14	1.51
Virginia	0.83	0.02	0.00	0.79	0.87
Washington	0.90	0.03	0.00	0.85	0.96
West Virginia	1.28	0.06	0.00	1.16	1.41
Wisconsin	1.01	0.02	0.71	0.97	1.05
Wyoming	0.62	0.01	0.00	0.60	0.64
Adult Education					
Less than high school	Reference				
High school degree or GED	0.98	0.20	0.92	0.65	1.47
Some college or technical school	0.95	0.15	0.75	0.69	1.30
College degree or higher	0.96	0.22	0.87	0.61	1.51
Sex of Adult					
Male	Reference				
Female	1.14	0.07	0.04	1.01	1.28
Mother Health Status					
Physical & mental health BOTH excellent/very good	Reference				
One or both of physical & mental health are NOT excellent/very good	0.73	0.08	0.00	0.59	0.89
No mother reported in the household	1.21	0.56	0.68	0.49	3.00
Parent Nativity					
Parent(s) born in US	Reference				
Any parent born outside US	0.75	0.05	0.00	0.65	0.86
Father Health Status					
Physical & mental health BOTH excellent/very good	Reference				
One or both of physical & mental health are NOT excellent/very good	0.88	0.08	0.17	0.73	1.06
No father reported in the household	1.22	0.37	0.50	0.68	2.21

Appendix D

Model building for study 2

Model 1

Coefficient estimates for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Coef. Est.	SE	p value	LL CI	UL CI
Sex of Child					
Male	0.02	0.01	0.02	0.00	0.03
Female	Reference				
Child Race/Ethnicity					
White, non-Hispanic	Reference				
Hispanic	-0.08	0.01	0.00	-0.10	-0.05
Black, non-Hispanic	-0.07	0.02	0.00	-0.11	-0.04
Asian, non-Hispanic	-0.07	0.02	0.00	-0.11	-0.03
American Indian or Alaska Native Non-Hispanic	-0.16	0.06	0.01	-0.27	-0.04
Native Hawaiian and Other Pacific Islander Non-Hispanic	-0.08	0.10	0.43	-0.28	0.12
Multi-Race Non-Hispanic	-0.03	0.02	0.03	-0.06	0.00
Other Non-Hispanic	0.06	0.07	0.40	-0.08	0.19
Born in USA					
Born in US	Reference				
Born outside of US	0.05	0.03	0.05	0.00	0.10
Child Age	-0.01	0.00	0.11	-0.01	0.00
Insurance Type					
Private health insurance only	Reference				
Public health insurance only	-0.14	0.01	0.00	-0.16	-0.12
Public and private insurance	-0.17	0.02	0.00	-0.21	-0.13
Currently uninsured	-0.20	0.02	0.00	-0.24	-0.15

Model 2

Coefficient estimates for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Coef. Est.	SE	p value	LL CI	UL CI
Sex of Child					
Male	0.01	0.01	0.09	0.00	0.03
Female	Reference				
Child Race/Ethnicity					
White, non-Hispanic	Reference				
Hispanic	-0.08	0.01	0.00	-0.10	-0.05
Black, non-Hispanic	-0.06	0.02	0.00	-0.10	-0.03
Asian, non-Hispanic	-0.07	0.02	0.00	-0.11	-0.03
American Indian or Alaska Native Non-Hispanic	-0.15	0.06	0.01	-0.26	-0.04
Native Hawaiian and Other Pacific Islander Non-Hispanic	-0.09	0.10	0.36	-0.29	0.10
Multi-Race Non-Hispanic	-0.03	0.02	0.04	-0.06	0.00
Other Non-Hispanic	0.05	0.07	0.44	-0.08	0.19
Born in USA					
Born in US	Reference				
Born outside of US	0.05	0.03	0.05	0.00	0.10
Child Age	0.01	0.00	0.14	0.00	0.01
Insurance Type					
Private health insurance only	Reference				
Public health insurance only	-0.11	0.01	0.00	-0.13	-0.09
Public and private insurance	-0.11	0.02	0.00	-0.15	-0.07
Currently uninsured	-0.19	0.02	0.00	-0.24	-0.15
Special Health Care Status					
Non-SHCN	Reference				
SHCN	-0.06	0.01	0.00	-0.08	-0.04
Child Health Status					
Excellent or very good	Reference				
Good	-0.21	0.02	0.00	-0.24	-0.18
Fair or Poor	-0.38	0.03	0.00	-0.44	-0.31

Model 3

Coefficient estimates for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Coef. Est.	SE	p value	LL CI	UL CI
Sex of Child					
Male	0.01	0.01	0.11	0.00	0.03
Female	Reference				
Child Race/Ethnicity					
White, non-Hispanic	Reference				
Hispanic	-0.07	0.01	0.00	-0.09	-0.04
Black, non-Hispanic	-0.05	0.02	0.01	-0.08	-0.01
Asian, non-Hispanic	-0.07	0.02	0.00	-0.11	-0.03
American Indian or Alaska Native Non-Hispanic	-0.12	0.06	0.03	-0.23	-0.01
Native Hawaiian and Other Pacific Islander Non-Hispanic	-0.08	0.10	0.40	-0.28	0.11
Multi-Race Non-Hispanic	-0.03	0.02	0.05	-0.06	0.00
Other Non-Hispanic	0.05	0.07	0.50	-0.09	0.18
Born in USA					
Born in US	Reference				
Born outside of US	0.05	0.03	0.03	0.01	0.10
Child Age	0.01	0.00	0.03	0.00	0.02
Insurance Type					
Private health insurance only	Reference				
Public health insurance only	-0.09	0.01	0.00	-0.11	-0.07
Public and private insurance	-0.10	0.02	0.00	-0.14	-0.06
Currently uninsured	-0.16	0.02	0.00	-0.21	-0.12
Special Health Care Status					
Non-SHCN	Reference				
SHCN	-0.07	0.01	0.00	-0.09	-0.06
Child Health Status					
Excellent or very good	Reference				
Good	-0.21	0.02	0.00	-0.24	-0.18
Fair or Poor	-0.38	0.03	0.00	-0.44	-0.31
Place for Usual Sick Care					
Doctor's Office	Reference				
Hospital Emergency Room	-0.07	0.05	0.12	-0.16	0.02

Model 3 Continued

Coefficient estimates for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Coef. Est.	SE	p value	LL CI	UL CI
Hospital Outpatient Department	-0.17	0.05	0.00	-0.27	-0.07
Clinic or Health Center	-0.07	0.01	0.00	-0.10	-0.05
Retail Store Clinic or 'Minute Clinic'	-0.16	0.04	0.00	-0.24	-0.09
School (Nurse's Office, Athletic Trainer's Office)	-0.23	0.06	0.00	-0.35	-0.10
Some other place	-0.29	0.06	0.00	-0.41	-0.18
Personal Nurse or Doctor					
Have at least one PDN	Reference				
Do not have a personal doctor or nurse	-0.20	0.01	0.00	-0.22	-0.18

Model 4

Coefficient estimates for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Coef. Est.	SE	p value	LL CI	UL CI
Sex of Child					
Male	0.02	0.01	0.03	0.00	0.03
Female	Reference				
Child Race/Ethnicity					
White, non-Hispanic	Reference				
Hispanic	-0.03	0.01	0.05	-0.05	0.00
Black, non-Hispanic	0.00	0.02	0.81	-0.04	0.03
Asian, non-Hispanic	-0.04	0.02	0.05	-0.08	0.00
American Indian or Alaska Native Non-Hispanic	-0.12	0.06	0.03	-0.23	-0.01
Native Hawaiian and Other Pacific Islander Non-Hispanic	-0.08	0.10	0.39	-0.28	0.11
Multi-Race Non-Hispanic	-0.01	0.01	0.72	-0.03	0.02
Other Non-Hispanic	0.08	0.07	0.22	-0.05	0.21
Born in USA					
Born in US	Reference				
Born outside of US	0.06	0.02	0.02	0.01	0.11
Child Age	0.03	0.01	0.00	0.02	0.04

Model 4 Continued

Coefficient estimates for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Coef. Est.	SE	p value	LL CI	UL CI
Insurance Type					
Private health insurance only	Reference				
Public health insurance only	-0.01	0.01	0.45	-0.03	0.02
Public and private insurance	-0.05	0.02	0.02	-0.09	-0.01
Currently uninsured	-0.12	0.02	0.00	-0.16	-0.07
Special Health Care Status					
Non-SHCN	Reference				
SHCN	-0.06	0.01	0.00	-0.08	-0.04
Child Health Status					
Excellent or very good	Reference				
Good	-0.16	0.02	0.00	-0.19	-0.13
Fair or Poor	-0.32	0.03	0.00	-0.38	-0.25
Place for Usual Sick Care					
Doctor's Office	Reference				
Hospital Emergency Room	-0.03	0.04	0.57	-0.11	0.06
Hospital Outpatient Department	-0.15	0.05	0.00	-0.25	-0.05
Clinic or Health Center	-0.06	0.01	0.00	-0.09	-0.04
Retail Store Clinic or 'Minute Clinic'	-0.17	0.04	0.00	-0.24	-0.10
School (Nurse's Office, Athletic Trainer's Office)	-0.21	0.06	0.00	-0.33	-0.09
Some other place	-0.26	0.06	0.00	-0.37	-0.15
Personal Nurse or Doctor					
Have at least one PDN	Reference				
Do not have a personal doctor or nurse	-0.19	0.01	0.00	-0.21	-0.17
Household Language					
English	Reference				
Non-English	-0.07	0.02	0.00	-0.11	-0.03
School Safety					
Definitely agree	Reference				
Somewhat agree	-0.12	0.01	0.00	-0.14	-0.10
Somewhat or definitely disagree	-0.46	0.03	0.00	-0.52	-0.41
Children age 0-5 years	0.01	0.01	0.38	-0.02	0.04

Model 4 Continued

Coefficient estimates for the association between number of parent-reported PFCC components as a function of socio-demographic/health characteristics, 2018-2019 National Survey of Children's Health

Characteristic	Coef. Est.	SE	p value	LL CI	UL CI
Neighborhood Safety					
Definitely agree	Reference				
Somewhat agree	-0.09	0.01	0.00	-0.10	-0.07
Somewhat or definitely disagree	-0.25	0.02	0.00	-0.29	-0.21
Family Structure					
Two parents, currently married	Reference				
Two parents, not currently married	-0.06	0.02	0.00	-0.10	-0.03
Single parent (mother or father)	-0.06	0.01	0.00	-0.08	-0.04
Grandparent Household	0.00	0.03	0.91	-0.05	0.05
Other relation	-0.07	0.05	0.13	-0.16	0.02
Federal Poverty					
0-99% FPL	-0.10	0.02	0.00	-0.13	-0.07
100%-199% FPL	-0.06	0.01	0.00	-0.08	-0.03
200%-399% FPL	-0.04	0.01	0.00	-0.06	-0.02
400% FPL or above	Reference				