



Family-Centered Care Measurement and Associations With Unmet Health Care Need Among US Children

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ABSTRACT

OBJECTIVE: Family-centered care (FCC), including shared decision making (SDM), has become increasingly emphasized in pediatric health care delivery. Past studies using national surveys have used different FCC measurement approaches without determining their validity. We, therefore, sought to develop an FCC measurement model with Medical Expenditure Panel Survey (MEPS) items previously used to assess FCC or SDM; and to determine temporal associations of FCC with unmet health care need.

METHODS: Four longitudinal MEPS data files (2007–2011) were combined. The study sample included 15,764 US children aged 0 to 17 years. Eight items assessed FCC, and 5 items assessed unmet health care need. We performed exploratory factor analyses to develop an FCC measurement model and fit a cross-lagged structural equation model to determine temporal associations between FCC and unmet health care need.

RESULTS: Results supported a 2-factor FCC model including family–provider communication and SDM. The family–provider communication factor was indicated by items reflecting general communication between the child's doctor

and family. The SDM factor was indicated by items reflecting decision-making about the child's health care. Adjusted cross-lagged structural equation model results showed family–provider communication and SDM were associated with a reduced likelihood of unmet health care need the following year. Unmet health care need was not significantly associated with family–provider communication or SDM the subsequent year.

CONCLUSIONS: Study results support differentiating between family–provider communication and SDM as interrelated aspects of FCC in future pediatric health care quality measurement and improvement. Family–provider communication and SDM may reduce the likelihood of unmet health care need the following year among US children.

KEYWORDS: family-centered care; pediatric health care quality measurement; shared decision making; structural equation modeling; unmet health care need

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WHAT'S NEW

Seven Medical Expenditure Panel Survey items were used to validly assess family-centered care, including family–provider communication and shared decision making (SDM). Family–provider communication and SDM were associated with a lower likelihood of unmet health care need the following year among US children.

with positive health care experiences,⁵ increased parent knowledge of health-promoting behaviors for children,⁶ reduced unmet health care needs,^{6,7} reduced acute care,^{8,9} increased preventive care utilization,^{7,9} and reduced out-of-pocket⁷ and inpatient medical expenditures.¹⁰ Yet FCC evidence remains limited as a result of inconsistent measurement approaches and a lack of heterogeneity in the populations studied.^{11–13} Determining and utilizing valid measures of FCC may help strengthen its evidence base while better enabling health systems to deliver quality care to children.

The Committee on Hospital Care and Institute for Patient- and Family-Centered Care defines FCC as an

FAMILY-CENTERED CARE (FCC) is an integral component of pediatric health care quality in the United States, as emphasized by federal health care legislation^{1,2} and population health priorities.^{3,4} FCC may be associated

“innovative approach to pediatric health care planning, delivery, and evaluation that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient’s life.”¹⁴ Key FCC principles include information sharing, respect and honoring differences, partnership and collaboration, negotiation, and care in the context of the family and community.¹⁵ In pediatric health care, FCC often occurs between children (patients), their family members, and their health care providers.^{14,15}

Health plan and national household surveys, including the Medical Expenditure Panel Survey (MEPS), have been used to assess FCC.^{5–10,16,17} FCC composite measures developed from these data sources have included similar items (Online Appendix A), but variation in FCC measurement approaches has yielded different prevalence estimates^{18,19} and associations of FCC with pediatric health care outcomes.^{6–10,19} Although FCC measurement approaches have been anchored to the American Academy of Pediatrics’ patient-centered medical home concept,⁴ only the construct validity of Consumer Assessment of Healthcare Providers and Systems (CAHPS) items used to measure FCC has been examined. Furthermore, the samples used to establish construct validity have not been nationally representative.^{16,20} There is, consequently, a need to establish FCC measurement validity among the broader US child population.

A significant need also exists to better understand how FCC and SDM may together drive pediatric health care outcomes on a large-scale basis. National surveys have assessed SDM using some FCC items (Online Appendix A) without explicitly acknowledging overlap in these 2 pediatric health care quality constructs.²¹ SDM is generally defined as a treatment decision-making model characterized by patient (child and family) and provider involvement, information sharing, and joint participation in the medical decision-making process including the expression of treatment preferences and agreement about the treatment or treatments to implement.²¹ Although SDM has been described as a pediatric health care quality construct unique from FCC in some frameworks, SDM has also been described as one FCC component.²²

This study aimed to determine an FCC measurement model using 8 MEPS items previously used to assess FCC or SDM; and to test the temporal association of the FCC factor with unmet health care need over the MEPS’ 2-year time frame among US children. We hypothesized a 1-factor FCC measurement model consisting of 8 items would best fit the data because prior research has used these 8 items in composite measures to indicate one underlying FCC construct.^{9,10,21,23} We further sought to test temporal associations of FCC with unmet health care need because establishing predictive validity is important in the development of a sound measurement model.²⁴ We chose unmet health care need as the outcome of interest because FCC is associated with reduced unmet health care need across different FCC and SDM measures using MEPS data.^{9,10,19,21,24} Other pediatric health care outcomes (eg, health services utilization, medical expenditures) have not

shown the same consistency in their associations with FCC.¹⁹ In line with prior research, we hypothesized FCC would be associated with reduced unmet health care need the following year.^{6,7,19} Together, this study’s findings stand to impact how FCC is validly measured and to clarify temporal associations of FCC with unmet health care need among US children.

METHODS

RESEARCH DESIGN

This study was an analysis of secondary data collected on a nationally representative sample of children aged 0 to 17 years. Parent-reported data on children were drawn from 4 MEPS longitudinal public use files (panels 12–15), spanning data collected from 2007 to 2011. Given the MEPS’ overlapping panel design,²⁵ approximately 2 years of data were available for each child. Oregon State University’s institutional review board determined this study was not human subjects research.

DATA SOURCE

We used the MEPS to determine an FCC measurement model for the following reasons: 1) MEPS items have been repeatedly used to assess FCC and SDM among US children,^{6,8–10,20,21} 2) some MEPS items previously used to measure FCC were adopted from CAHPS, which is widely used by health plans,²⁶ 3) the MEPS provides 2 years of data on each child in the sample, allowing for longitudinal analysis, and 4) the MEPS has been conducted annually since 1996, unlike other surveys containing FCC measures. The Federal Agency for Healthcare Research and Quality (AHRQ) sponsors the MEPS, which is a complex national probability survey. This study used the Household Component. The survey’s sampling design and data collection process are documented elsewhere.²⁵ Overall response rates for the data files used ranged from 53.5% to 59.3%.²⁷

SAMPLE

A total of 17,383 US children aged 0 to 17 years in the first survey year were initially identified. Of these children, 1619 (8.2%) were missing data for all 8 items used to measure FCC in the first survey year because they either had “do not know” or “refused” responses to all 8 items ($n = 11$) or because they both lacked a usual source of care* and had not visited a doctor’s office or clinic to get health care in the past year ($n = 1608$). These children were excluded in analyses using the FCC variables. The final study sample included 15,764 children with any data on 8 of the FCC items in the first survey year.

*In the MEPS—Household Component, usual source of care is defined as “whether or not [individuals] or their family member had a particular doctor’s office, clinic, health center, or other place (excluding hospital emergency rooms) to go to for medical care when ill or for health-related advice.”^{34(p2)}

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