Racial and Ethnic Disparities in Unmet Need for Pediatric Therapy Services: The Role of Family-Centered Care

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ABSTRACT

OBJECTIVE: To examine whether individual elements of family-centered care (FCC) mediate racial/ethnic disparities in parent-reported unmet therapy need.

METHODS: We conducted a secondary data analysis using the 2009–2010 National Survey of Children With Special Health Care Needs. A total of 6478 black, Hispanic, and white children ages 0 to 5 years had complete data on parent-reported unmet need and FCC. Five measured indicators of FCC included whether the child's health care provider spent enough time with the child (time), listened carefully to the child's parents (listening), was sensitive to family culture and values (sensitivity), delivered information specific to the child's health (information), and helped parents feel like partners (partnership). We performed staged multivariate logistic regression to test the association between race/ethnicity and parent-reported unmet therapy need, and to explore whether this association was mediated by elements of FCC using the Baron-Kenny mediation framework.

RESULTS: Eighteen percent of children with special health care needs 0 to 5 years old with reported therapy need experienced unmet need. Black and Hispanic children were more likely than white children to have parent-reported unmet therapy need (adjusted odds ratio 1.59, 95% confidence interval 1.08–2.36). This disparity was no longer significant after adjustment for the FCC elements of time, sensitivity, or partnership.

CONCLUSIONS: The provision of FCC is likely an important factor in meeting the therapy needs of children with developmental delay and in reducing racial/ethnic disparities in parent-reported unmet therapy need. Interventions aimed at fostering parent–provider relationships through improved cultural sensitivity and engagement of parents as partners are necessary to ensure equitable utilization of these services.

KEYWORDS: cultural sensitivity; developmental delay; shared decision making

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WHAT'S NEW

Black and Hispanic children are more likely than white children to experience unmet therapy need. Whether providers are perceived as spending enough time with families, being sensitive to families' cultures, or engaging parents as partners may reduce this disparity.

AN ESTIMATED 15% of children in the United States experience developmental disability (DD),[1,2] a complex phenomenon appearing early in life and resulting from the dynamic interaction between a child's health condition and contextual factors. DDs manifest as impairments in motor, language, cognitive, or behavioral development that affect children's ability to participate in age-appropriate activities throughout much of their life. Pediatric therapy services such as physical, occupational, or speech therapy for children with DD have been shown to optimize development and minimize subsequent disability[3,4] while empowering families.[5]

Given the importance of pediatric therapy services early in a child's life, the US federal government has mandated early intervention and special education through Parts C and B of the Individuals With Disabilities Education Act (IDEA), respectively. Despite this federal mandate, 43% children with DD under the age of 5 in the United States have unmet needs for pediatric therapy services, defined as having either unrecognized therapy need or parent-reported unmet therapy need (among children with recognized therapy needs).[6] Moreover, the burden of unmet need for pediatric therapy services falls disproportionately among black and Hispanic children, as well as children from other racial or ethnic groups.[6] Measures of pediatric health care access and quality show similar findings,[7–11] with black and Hispanic children, and children from other racial or ethnic groups less likely than their white counterparts to access important health services[6,12–14] or receive quality family-centered care (FCC) through the pediatric medical home.[15–17]

Attention has shifted from documenting differences between racial and ethnic groups to understanding the mechanisms underlying these pervasive health care disparities. While various predisposing, enabling, and functional need characteristics are associated with reductions in racial/ethnic disparities in pediatric health services,[18,19] contextual factors, such as the provision of FCC, also play an important role.[12,20,21] FCC, a central tenet of the pediatric medical home, is defined as a respectful family–professional partnership that "honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship."[22] Evidence supports the role of FCC in improving health care access and reducing unmet health care needs among children.[21,23–27] However, whether individual elements of FCC are associated with reductions in racial/ethnic disparities in parent-reported unmet need for pediatric therapy services has not been explored.

The objective of our study was to explore whether individual elements of FCC mediate racial/ethnic disparities in parent-reported unmet therapy need among children with DD.

METHODS

DATA SOURCE, POPULATION, AND STUDY SAMPLE

Data were obtained from the 2009–2010 National Survey of Children With Special Health Care Needs (NS-CSHCN), a random-digit-dial telephone survey funded by the Maternal and Child Health Bureau within the Health Resources and Services Administration, and conducted by the Centers for Disease Control and Prevention's National Center for Health Statistics.[28] The survey utilizes the State and Local Area Integrated Telephone Survey mechanism to produce a nationally representative sample of noninstitutionalized US CSHCN younger than 18 years. The primary sampling unit was the household, and children were screened for special health care needs using a validated CSHCN screener.[29] CSHCN were defined as having 1 or more criteria associated with a chronic health condition: ongoing need for prescription medications; need for more medical care, mental health, or educational services than is usual for most children of the same age; limited or prevented in their ability to do the things most children of the same age can do; need for physical, occupational, or speech therapy; and/or having any emotional, developmental, or behavioral problem that requires treatment or counseling. Of the 372,698 children screened, 40,242 children were categorized as having special health care needs and completed the full interview. The interview completion rate among households known to include a CSHCN was 80.8%.[30] Given the importance of early identification and intervention for children with DD, we limited our sample to children from birth through age 5 years ($n = 7291$). A formal review and exemption for this secondary data analysis were obtained from the Johns Hopkins institutional review board.

VARIABLES

DEPENDENT VARIABLE

Parent-reported unmet need for pediatric therapy services was ascertained using 2 questions: "During the past 12 months/since [his/her] birth, was there any time when [your child] needed physical, occupational, or speech therapy?" and if yes, "Did [your child] receive all the therapy that he/she needed?" Children with negative responses to this final question were categorized as having parent-reported unmet therapy needs.

INDEPENDENT VARIABLES

The primary independent variable was race/ethnicity of the child. We initially created 4 distinct racial/ethnic categories: non-Hispanic white, non-Hispanic black, Hispanic, and other (American Indian, Alaska Native, Native Hawaiian, Pacific Islander, and Asian). The "other" group was removed from subsequent analyses as a result of small numbers in each subgroup and heterogeneity. With respect to black and Hispanic children, there were no quantitative differences observed between groups when compared to white children. Given this finding, we combined non-Hispanic black and Hispanic groups of children to achieve greater statistical efficiency. Additional predisposing factors, functional need factors, and enabling health care factors were identified according to the Behavioral Model of Health Services Utilization (Table 1).[31]

Predisposing factors included the child's age, gender and family income, as well as the number of CSHCN living in the household. Functional need factors included the number of parent-reported functional difficulties and condition stability. Enabling health care factors included whether or not the child had a personal doctor or nurse, was continuously covered by insurance over the past year, or received developmental services. All covariates were retained in fully adjusted models.

MEDIATING CONTEXTUAL VARIABLES

FCC has previously been operationalized using a scoring algorithm developed for use in the NS-CSHCN and employed in multiple national studies.[15,16,20,32–34] FCC is measured using 5 elements that describe providers' behaviors: "how often 1) did [your child's] doctors and health care providers spend enough time with him/her [time]; 2) did [your child's] doctors and health care providers listen carefully to you [listening]; 3) are they sensitive to your family's values and customs [sensitivity]; 4) did you get the specific information you needed from [your child's] doctors and other health care providers [information]; and 5) did [your child's] doctors or other health care providers help you feel like a partner in his/her care [partnership]. These individual elements of FCC are the focus of the current study, and responses of "usually" or "always" indicated receipt of that particular element of FCC.

ANALYTIC APPROACH

STATISTICAL ANALYSIS

We conducted bivariate chi-square analyses to explore the extent of racial/ethnic disparities in parent-reported unmet therapy need. We then performed staged multivariate logistic regression to test the association between race/