Parent-Reported Quality of Preventive Care for Children At-Risk for Developmental Delay

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Received for publication January 24, 2012; accepted May 10, 2012.

ABSTRACT

OBJECTIVE: To compare preventive care quality for children at risk and not at risk for developmental, behavioral, or social delays.

METHODS: Using the 2007 National Survey of Children's Health (n = 22,269), we used the Parents' Evaluation of Developmental Status (PEDS) questionnaire to identify children ages 10 months to 5 years who were at risk for delays. We examined parent-reported quality measures to evaluate whether care was comprehensive, coordinated, family-centered, effective in providing developmental surveillance and screening, and provided within a medical home. Bivariate and multivariate analyses were used.

RESULTS: Twenty-eight percent of children were at-risk for delay, with 17% at moderate risk and 11% at high risk. Greater proportions of children at high, moderate, and no/low risk had a usual source of care (89%–96%) and a personal doctor/nurse (91%–94%); smaller proportions of children underwent a standardized developmental screening (16%–23%) and had parental developmental concerns elicited from their doctor (47%–48%). In adjusted analyses, moderate-risk and high-risk children were less likely than no/low-risk children to receive needed care coordination (adjusted odds ratio [AOR] for high risk 0.33, 95% confidence interval [95% CI] 0.24–0.46) and referrals (high risk AOR 0.40, 95% CI 0.25–0.65), family-centered care (high-risk AOR 0.47, 95% CI 0.36–0.62), and to have a medical home (high-risk AOR 0.41, 95% CI 0.32–0.54).

CONCLUSIONS: Our findings may reflect either poorer quality of care provided to at-risk children, or higher level of parental need that routine visits are not currently meeting. For at-risk children, enhanced screening and detection followed by targeted increases in communication and follow-up may help clinicians better anticipate families' needs.

KEYWORDS: developmental delay; developmental screening; preventive care; quality

ACADEMIC PEDIATRICS 2012;12:384–390

WHAT'S NEW

Children at-risk for developmental, behavioral, and social delay receive lower quality care when compared with not-at-risk children. Our findings may reflect a higher level of parental need that routine visits are not meeting.

INTRODUCTION

PREVENTIVE CARE VISITS during the first 5 years of a child's life are critical. These visits may be the only opportunity to identify and address important developmental, behavioral, and social (henceforth referred to as simply developmental) delays before a child enters school. Poor quality of preventive care may hinder early identification of children at-risk for developmental delays (DD). At-risk children should be identified through surveillance and standardized screening at preventive visits and receive appropriate and timely intervention.[1–5]

The quality of preventive care provided to U.S. children suffers various deficiencies in its structures (eg, organization, personnel) and processes (eg, provision of care, receipt of care). For example, just one-half of parents nationwide report that their doctors ask about their developmental concerns, and less than one-fifth of children receive a standardized screening for DD.[6,7] One-third of children do not receive care that is family-centered at visits—parents report that doctors don't spend enough time, listen carefully, or provide them with needed information during visits.[8] More than 40% of children do not receive comprehensive and coordinated care through a medical home.[8] These key elements of quality are important for all children and may be critical to reducing the missed opportunities in care for children with or at risk for DD. Studies have documented significant delays in the diagnosis of DD and in the receipt of services for many of these children.[9–16] Children at risk for delay may have greater need for services at preventive visits. In a sample of South Carolina Medicaid children, mean age at first diagnosis of DD was 4.08 to 4.27 years, with more than 25% diagnosed after their fifth birthday, creating a missed opportunity for early intervention.[15] Among a national sample of children, just 10% of children with DD were receiving intervention services.[17]

Few data, however, are available on specific aspects of quality that are deficient in the care of children at risk for

DD. That is, do children who are at risk for DD receive high-quality preventive care that can help ensure that their developmental needs are met? If not, what specific aspects of quality are most in need of attention for this population of children? These data could help us design preventive care to more adequately meet the needs of children at risk for DD.

In this article, we compare the quality of preventive care for children at risk and not at risk for DD. In examining quality, we focus on structures and processes of care in preventive visits, including having care that is comprehensive, coordinated, family-centered, and effective in providing recommended developmental screening and surveillance. Because the medical home has been shown to be a key contributor to high-quality care and a potential vehicle for reducing disparities in care, we will also compare the existence of a medical home for children at risk and not at risk for DD.[8,18]

METHODS

PROCEDURES

We used data from the 2007 National Survey of Children's Health (NSCH),[19] a telephone survey sponsored by the U.S Department of Health and Human Services Maternal and Child Health Bureau and conducted by the National Center for Health Statistics. It uses the State and Local Area Integrated Telephone Survey system; the dataset provides detailed representative data at national and state levels on the health and well-being of U.S. children.

The NSCH is a random digit-dial sample of U.S. households with children younger than 18 years old in all 50 states and the District of Columbia. In households with 1 or more children younger than 18 years, one child was randomly selected as the target of a detailed interview with a parent/guardian (henceforth referred to as "parent") who was knowledgeable about the child's health and health care. Interviews were conducted from April 2007 to July 2008. The questionnaire was translated into Spanish, Mandarin, Cantonese, Vietnamese, and Korean. The weighted overall response rate was 46.7%. Details on NSCH methodology can be found elsewhere.[20]

The NSCH dataset contains parent-reported information on 91,642 children ages 0 to 17 years. 22,388 children are ages 10 months to 5 years; our study focuses on 22,269 of these children for whom a parent answered DD risk questions.

MEASURES

AT RISK FOR DD

To determine the degree to which children are at risk for DD, the NSCH uses questions derived from the Parents' Evaluation of Developmental Status (PEDS).[21] The PEDS is widely used in pediatric practice; it asks parents whether they have a concern about aspects of their child's learning, development, or behavior. The tool is a specific and sensitive indicator of a child's DD risk.[22,23] In the NSCH, a research version of the PEDS was used; parents of children 4 months to 5 years answered 8 questions with response options of being concerned "a lot", "a little", or "not at all". Responses of "a little" or "a lot" qualify as having a concern. Using the PEDS scoring method, we scored parental responses to identify children at high, moderate, and no/low-risk for delay. We calculated a Cronbach's alpha for the NSCH sample; it was 0.90, suggesting good internal consistency.[24]

MEASURES OF QUALITY

For each quality measure, we used NSCH questions and scoring algorithms; these were developed under the leadership of U.S Department of Health and Human Services Maternal and Child Health Bureau and designed to reflect the American Academy of Pediatrics' definition of the medical home and its components, as well as nationally-recommended quality indicators.[19,25]

Comprehensive and coordinated care.—We used the following dichotomous measures: whether 1) the child had a personal doctor or nurse, 2) the child had a usual source of care for sick and well visits, 3) the parent received needed help with care coordination, and 4) the parent received needed referrals without problem.

Family-centered and culturally effective care.—Parents who reported a visit for their child in the previous 12 months were asked if their doctor: 1) spends enough time, 2) listens carefully, 3) provides care that is sensitive to the family's values and customs, 4) provides needed information, 5) helps the family feel like a partner in their child's care, and 6) for parents who report a non-English primary language spoken at home, provides interpreter services when needed. Children whose parents responded "usually" or "always" to all 5 questions, and when applicable, the sixth, were categorized as having family-centered care.

Medical home.—Children were categorized as having a medical home if they had all 5 components of care described previously: 1) a personal doctor or nurse, 2) a usual source of care, 3) family-centered care, 4) care coordination if needed, and 5) no problems receiving needed referrals.

Elicitation of parental developmental concerns and developmental screening.—To gather data on the elicitation of parental developmental concerns during visits, parents of children who made a visit to the doctor in the past 12 months were asked: "During the past 12 months, did your child's doctors or other health care providers ask if you have concerns about his/her learning, development, or behavior?" To assess the receipt of developmental screening during visits, parents of children 10 months to 5 years who had a visit in the past 12 months were given a 3-item measure to determine whether they completed an age-appropriate standardized developmental screening tool in the past 12 months. Parents were asked whether they completed such a questionnaire and if the questionnaire contained age-appropriate questions about their child's development, communication, or social behavior. Children of parents who answered yes for all 3 components were