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

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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

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

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(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 categorized as having had a standardized developmental screening.

Analysis

Our analysis focuses on children ages 10 months to 5 years because this is the age range covered by all of our main measures of interest. We used bivariate analyses to examine the proportion of children who were at no/low, moderate, and high risk for delay. We used logistic regression to examine differences between quality measures by DD risk level in unadjusted and adjusted analyses. In adjusted analyses, we included covariates, on the basis of previous studies that may confound the relationship between our quality measures and DD risk. These included child race/ethnicity (Hispanic/Latino and non-Latino Black/ African-American, non-Latino white, non-Latino multiracial, and non-Latino other race/ ethnicity), child gender and age (categorized as 10–23, 24–47, and 48–71 months), household income as a percent of the federal poverty level (FPL; 0%–99%, 100%–199%, 200%–399%, and $ 400%), parental education for the parent in the household with the highest educational attainment (< high school, high school completion, and some college/ college degree), primary language spoken at home (English or another language), child health insurance status (uninsured, privately insured, or publicly insured), and special health care need as determined by the Children with Special Health Care Needs (CSHCN) Screener.6–8,26–28 We used the NSCH single imputation data file for income data; there is an 8.5% missing rate for this variable without imputation.

All analyses used NSCH weights to account for potential nonresponse bias and noncoverage of households without a telephone and to provide national estimates. Analyses were conducted using Stata/SE version 11 (StataCorp LP, College Station, TX) to adjust for the complex survey design.

Results

At risk for DD

Twenty-eight percent of children were at risk for DD, with 17% at moderate risk and 11% at high risk. There were significant differences by child and family characteristics for children at risk (moderate or high risk) versus not risk (no/low risk; Table 1). Nonwhite race/ ethnicity, poverty, lower parental educational level, non-English primary language households, male gender, older child age, special health care needs, and public insurance were all associated with being at risk for delay.

Effective Care

Elicitation of Parental Developmental Concerns and Developmental Screening—In each risk category, fewer than one-half of parents reported having their developmental concerns elicited by their child's doctor (47%–48%; Table 2). Twenty percent of children with no/low risk, 16% of children at moderate risk, and 23% of children at high risk had a parent report of a standardized developmental screening. The odds of having parental developmental concerns elicited were similar for moderate and high risk compared with no/ low risk children, and the unadjusted and adjusted odds of having a standardized developmental screening was lower for moderate risk compared with no/low risk children.

Comprehensive Care

Similarly high proportions of children in each risk category had a usual source of care (89%–96%) and a personal doctor or nurse (91%–94%; Table 2). The unadjusted and adjusted odds of having a usual source of care were significantly lower for moderate risk compared with no/low risk children.

Coordinated Care

Seventy-eight percent of no/low risk children received needed care coordination, compared with 63% for moderate-risk and 51% for high-risk children. Moderate-risk and high-risk children had lower unadjusted and adjusted odds of receiving needed care coordination than their no/low-risk counterparts. Eighty-nine percent of no/low-risk children, 82% of moderate-risk, and 74% of high-risk children received needed referrals without problem. High-risk children had lower unadjusted and adjusted odds of receiving needed referrals compared with no/low-risk children.

Family-Centered Care

The differences in the proportion of children at high-risk versus no/low-risk of DD for having each component of family-centered care ranged from 10 to 17 percentage points; the difference between high and no/low-risk in the composite measure for family-centered care was 24 percentage points (Table 3). In unadjusted and adjusted regression analyses, parents of children at moderate and high risk were less likely to report that their doctor usually or always spends enough time with them, listens carefully, provides them with needed information, shows sensitivity to the family’s values and customs, and helps the parent feel like a partner in care.

Medical Home

Sixty-nine percent of children at no/low risk, 55% at moderate risk, and 38% at high risk met all criteria for a medical home (Table 4). At-risk children had lower unadjusted and adjusted odds of meeting medical home criteria compared with not-at-risk children.

Discussion

The quality of preventive care provided to U.S. children at-risk for DD varied widely. Receipt of standardized developmental screening and elicitation of parental developmental concerns were quite low for children at all DD risk levels; however, children at moderate and high risk were significantly less likely than those at no/low risk to receive family-centered care and its individual components or to receive effective care coordination and problem-free referrals when they were needed. Because of low levels of quality in these areas, at-risk children were much less likely to meet criteria for having a medical home.

Although the level of parent-reported elicitation of developmental concerns and developmental screening was similar for at-risk and not-at-risk children, it is important to note that overall the receipt of these services was low. A low level of receipt of developmental services has been documented in previous studies,6,7,29,30 although there is some evidence that pediatricians’ practice is improving in this area.31 Our current study illustrates that this low level of quality is similar among children regardless of their developmental risk as measured by a parent-reported scale. In addition, data are available to suggest that receipt of these services is particularly critical for children at high risk for delay, as screening is associated with greater likelihood of receiving early intervention services.7

For developmental screening and usual source of care, we report a statistically significant difference in adjusted odds for either moderate or high-risk children. However, the small differences in these variables by child risk (4%–5%) indicate little disparity.

Parents of at-risk children reported lower quality of care experiences than parents of not-at-risk children across 5 family-centered care components. These measures are critical because they describe parents' perceptions of and experiences with the care received. These findings may reflect either less family-centered care provided to at-risk children compared with not-at-risk children, or greater family-centered care needs or expectations among parents of at-risk children that the current visit structure is not meeting. Two family-centered care components (provider "spends enough time" and "provides needed information") showed the widest difference between high- and no/low-risk children in bivariate analysis. This finding is fairly consistent with previous studies on family-centered care disparities for other vulnerable populations of children and may signal 2 important areas of need in addressing disparities for children at-risk for DD.[32,33]

Because our data show that at-risk children are receiving the same (albeit low) level of developmental screening and elicitation of concerns as not-at-risk children, it is possible that this lower level of parent-perceived family-centeredness of care is more related to needs than actual care received. Our current structure of preventive care may not be designed to adequately meet the higher-intensity needs of at-risk children. Parents of at-risk children may have greater need for longer, more detailed, and more frequent discussion with their providers regarding their child's development and behavior. The structure of preventive care may therefore need to be redesigned to meet the needs of these families; these structural changes may include tiered services for at-risk and not-at-risk children, enhanced communication with parents both during and outside of the visit, longer in-office visits for at-risk children, use of a team-based approach to care that relies on non-physician staff to provide adjunct services, and provision of some services through non-face-to-face visit transactions. These types of structural changes may not only improve care of at-risk children with a greater level of need but may also improve the delivery of services that a majority of children, regardless of developmental risk, are not yet receiving under our current preventive care structure.

Our finding, that at-risk children were less likely to receive needed care coordination and referrals, points to another area of need for children at-risk for DD. Parents of at-risk children may require a more advanced level of coordination and referral help than not-at-risk children because of a greater need for services. It may be that these families have more complex needs in coordination and referral that our system cannot adequately address, or that the parents of at-risk children don't have the same resources and capacities as parents of not-at-risk children to accomplish the same referral and care coordination goals.

Finally, because of poor quality with respect to family-centered care and care coordination/ referrals, children at-risk for delay were much less likely to have a medical home. This is a critical area of need. Access to a medical home is associated with better outcomes for CSHCN, and an increased likelihood that all children receive necessary preventive care services and have fewer unmet healthcare needs.[8,18]

There are several limitations to this study. Although we focused on preventive care quality, some of our measures may pertain more broadly to primary care. These measures, however, are applicable and critical to preventive care and to follow-up of DD identified at preventive visits. We used a parent-reported screening tool to determine DD risk. Other tools measure the level of delay (ie, quantitative developmental age); however, these tools are time-consuming, need to be administered directly to the child, and are not used in the NSCH.[5] The estimated prevalence of DD in studies using these types of tools is much lower than the proportion of children at-risk identified by the PEDS.[17] In addition, use of the PEDS may have resulted in overestimation (eg, parents may be more likely to report developmental concerns not related to delay if they were not addressed in visits) or underestimation (eg, parents may not recognize when a developmental concern is present) of the number of children at-risk for delay. Although we included household language in our multivariate analyses, some data suggest that parents from non-English primary language households may respond differently to the PEDS.28 Similar to previous studies,6,15 we found differences in the rate of DD risk by child characteristics (eg, race/ethnicity); however, we did not examine these differences in multivariate models, as it was not the focus of our study.

Despite these limitations, our findings have important implications for clinical practice. First, because the overall quality of developmental services received by parents of at-risk and not-at-risk children was consistently low, pediatric healthcare professionals may have to consider more fundamental reforms to the provision of developmental services than are commonly proposed; these may include many of the structural changes to preventive care suggested above. Next, when children are identified as at-risk for DD, clinicians may need to find new ways to enhance education, counseling, and guidance, and improve coordination of care and referrals for these parents outside of the typical preventive visit, which does not seem to be meeting the needs of these parents.

Preventive visits during early childhood provide a critical opportunity to identify and address DD. Preventive care must be structured in a way that prevents this important opportunity from being missed, especially for the most vulnerable children—those who are at-risk for delay and who may have few other opportunities for identification of delays before starting school.

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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.

Table 1

U.S. Children at Risk for Delay, Ages 10 Months to 5 Years

	No/Low Risk for Delay, (72% of sample)	**Moderate Risk for Delay, (17% of sample)**	**High Risk for Delay (11% of sample)**	***P* Value**
Total sample (N = 22,269)	–	–	–	
Race/ethnicity (N = 21,933)				<.001
African-American	12	14	18	
Latino	19	26	34	
Non-Latino white	59	50	37	
Non-Latino multiracial	6	5	4	
Other	5	4	7	
Gender (N = 22,254)				.002
Male	50	55	58	
Female	50	45	42	
Child age (N = 22,269)				<.001
<2 years	25	23	15	
2–3 years	38	33	31	
4–5 years	37	44	54	
Poverty level (N = 22,269)				<.001
0%–99%	18	22	31	
100%–199%	21	23	29	
200%–399%	30	30	22	
400% and greater	31	25	18	
Highest educational level (N = 21,599)				<.001
Less than high school	7	12	18	
Completion of high school/some college	21	22	30	
$ 4-year college degree	71	66	52	
Household language (N = 22,252)				<.001
English	87	81	72	
Other language	13	19	28	
Health insurance status (N = 22,065)				<.001
Public Insurance (State Children's Health Insurance Program, Medicaid)	31	38	51	
Private insurance	62	54	39	
Uninsured	7	8	9	
Special health care need (N = 22,269)				<.001
No	90	83	71	
Yes	10	17	29	

Percentages may not add to 100 due to rounding.

Differences in total N among variables are due to missing data.

Table 2

Odds Ratio of Having Care That Is Effective, Comprehensive, and Coordinated for U.S. Children at No/Low, Moderate, and High Risk for Developmental, Behavioral, and Social Delay

	% With Outcome	Unadjusted Odds Ratio (95% CI)*	Adjusted Odds Ratio (95% CI)*†
Effective‡			
Parental developmental concerns elicited			
No/low risk	48	Referent	Referent
Moderate risk	47	0.95 (0.79–1.14)	1.01 (0.84–1.22)
High risk	47	0.95 (0.77–1.18)	1.24 (0.97–1.58)
Standardized developmental screen received			
No/low risk	20	Referent	Referent
Moderate risk	16	0.80 (0.65–0.98)§	0.78 (0.63–0.97)§
High risk	23	1.25 (1.00–1.57)	1.17 (0.91–1.50)
Comprehensive			
Has a usual source of care			
No/low risk	96	Referent	Referent
Moderate risk	91	0.45 (0.30–0.69)§	0.53 (0.34–0.81)§
High risk	89	0.39 (0.25–0.60)§	0.64 (0.38–1.05)
Has a personal doctor or nurse			
No/low risk	94	Referent	Referent
Moderate risk	93	0.83 (0.61–1.14)	1.00 (0.71–1.42)
High risk	91	0.57 (0.41–0.81)§	0.83 (0.56–1.23)
Coordinated			
Receives needed, effective care coordination			
No/low risk	78	Referent	Referent
Moderate risk	63	0.49 (0.36–0.68)§	0.56 (0.41–0.76)§
High risk	51	0.30 (0.22–0.40)§	0.33 (0.24–0.46)§
Receives needed referrals without problems			
No/Low Risk	89	Referent	Referent
Moderate risk	82	0.57 (0.28–1.17)	0.77 (0.47–1.26)
High risk	74	0.35 (0.23–0.54)§	0.40 (0.25–0.65)§

[*] Odds ratio of outcome for at-risk children compared with no/low-risk children.

[†] Adjusted for child race/ethnicity, age, gender, health insurance type, household poverty level, highest educational attainment, primary language spoken at home, and child special health care need.

[‡] Effective in providing recommended developmental screening and surveillance.

[§] Significant findings.

Table 3

Odds Ratio of Having Family-Centered Care Among U.S. Children at No/Low, Moderate, and High Risk for Developmental, Behavioral, and Social Delay

	% With Outcome	**Unadjusted Odds Ratio (95% CI)[*]**	**Adjusted Odds Ratio (95% CI)[*†]**
Family-centered care (composite measure)[‡]			
No/low risk	77	Referent	Referent
Moderate risk	66	0.58 (0.47–0.71)[§]	0.65 (0.52–0.80)[§]
High risk	53	0.34 (0.27–0.42)[§]	0.47 (0.36–0.62)[§]
Elements of family-centered care[¶]			
Doctors spend enough time			
No/low risk	86	Referent	Referent
Moderate risk	79	0.62 (0.49–0.79)[§]	0.74 (0.56–0.97)[§]
High risk	69	0.38 (0.30–0.49)[§]	0.59 (0.44–0.78)[§]
Doctors listen carefully			
No/low risk	94	Referent	Referent
Moderate risk	89	0.57 (0.42–0.77)[§]	0.65 (0.47–0.92)[§]
High risk	83	0.33 (0.24–0.46)[§]	0.46 (0.32–0.67)[§]
Doctors provide needed information			
No/low risk	91	Referent	Referent
Moderate risk	85	0.59 (0.44–0.79)[§]	0.66 (0.50–0.88)[§]
High risk	76	0.32 (0.24–0.42)[§]	0.43 (0.31–0.58)[§]
Doctors are sensitive to family's values and customs			
No/low risk	93	Referent	Referent
Moderate risk	87	0.54 (0.41–0.72)[§]	0.63 (0.46–0.86)[§]
High risk	82	0.36 (0.26–0.48)[§]	0.51 (0.36–0.73)[§]
Doctors help parent feel like a partner in care			
No/low risk	93	Referent	Referent
Moderate risk	89	0.61 (0.46–0.80)[§]	0.70 (0.52–0.93)[§]
High risk	82	0.34 (0.25–0.47)[§]	0.46 (0.33–0.65)[§]

[*] Odds ratio of outcome for at-risk children compared to no/low-risk children.

[†] Adjusted for child race/ethnicity, age, gender, health insurance type, household poverty level, highest educational attainment, primary language spoken at home, and child special health care need.

[‡] For FCC composite measure, n = 21,981.

[§] Significant findings.

[¶] We did not perform separate analyses for the family-centered care component of receiving needed interpreter services because this question was only asked of a small proportion of our sample; this item is included in the family-centered care composite measure.

Table 4

Odds Ratio of Having a Medical Home Among U.S. Children at No/Low, Moderate, and High Risk for Developmental, Behavioral, and Social Delay

Medical Home Criteria Met[*]	% With Outcome	Unadjusted Odds Ratio (95% CI)[†]	Adjusted Odds Ratio (95% CI)[†‡]
No/low risk	69	Referent	Referent
Moderate risk	55	0.55 (0.46–0.67)[§]	0.63 (0.52–0.76)[§]
High risk	38	0.29 (0.23–0.36)[§]	0.41 (0.32–0.54)[§]

[*] The child has a personal doctor or nurse, a usual source of care for well and sick visits, and receives family-centered care, needed care coordination, and has no problems getting needed referrals. Total N = 21,629.

[†] Odds ratio of outcome for at-risk children compared to no/low-risk children.

[‡] Adjusted for child race/ethnicity, age, gender, health insurance type, household poverty level, highest educational attainment, primary language spoken at home, and child special health care need.

[§] Significant findings.