Parents with Low Literacy Report Higher Quality of Well-Child Care

By

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Abstract

Introduction

The growing literature on improving pediatric quality of care has highlighted the gaps in quality by socioeconomic status. Literacy may be an important factor within the relationship between socioeconomic status and quality healthcare. As young children depend on their parents for healthcare services, we hypothesized that low parental literacy would be associated with poor well-child healthcare.

Methods

Our design was a cross-sectional survey using face-to-face interviews of caregivers of 1-4 year old children in a pediatric resident clinic in the Southeast. We used the Rapid Estimate of Adult Literacy in Medicine to assess parental literacy and four subscales relevant to either provider-parent relationships or content of discussions in the well-child visit from the Promoting Healthy Development Survey to assess the quality of the well-child appointment.

<u>Results</u>

The mean age of the 150 respondents was 30 years, 56% were African American, 68% received Medicaid, and 86% graduated high school. Thirty-four percent of the respondents scored below a 9th grade reading level (low literacy). Parents with low-literacy were more likely than those with normal or high literacy to report family centered care (55% versus 27%, p=0.001), and helpfulness and confidence (84% versus 56%, p<0.001). There was no difference, by literacy level, in the mean percent of family well-being topics discussed or the mean percent of anticipatory guidance topics for which the parents had their informational needs met.

Discussion

The low-literacy respondents reported higher quality than the normal/high literacy group regarding relationships and there was no difference in quality by literacy level regarding content of discussions. Potential mechanisms for the difference between low and high literacy groups include that parents with low-literacy may have lower expectations regarding relationships with their healthcare provider or pediatric residents may be more effective at relationship building with low-literacy families.

INTRODUCTION

Measuring pediatric quality of care is among the first steps to improve quality and reduce disparities.¹ The growing literature on improving pediatric quality of care has highlighted the gaps in quality by socioeconomic status. Children with low income are more likely to have parents report difficulty getting necessary care, difficulty getting specialist care, not being listened to, and not being respected. The children are more likely to be hospitalized for ambulatory-sensitive conditions, such as asthma.²⁻⁷ Although we have an incomplete understanding of the relationship between socioeconomic status and quality healthcare, literacy may be an important factor.In adults, health and quality of care are associated with literacy. Specifically, low literacy is associated with poor health knowledge,⁸⁻¹⁰ poor receipt of preventive services,¹¹ increased hospitalization,^{12, 13} increased complications from diabetes,¹⁴ and poor self-reported health status.^{15, 16}

In pediatrics, few researchers have studied the association between either child health or quality of pediatric healthcare and parental literacy, and they found mixed results. Parental low literacy has been associated with decreased breastfeeding,¹⁷ worse glycemic control for

diabetic children,¹⁸ and parental report of a greater degree of illness in the child.¹⁹ On the other hand, parental literacy was not related to parental report of use of pediatric preventive services or parental ability to follow medical instructions for the child.¹⁹

The majority of healthcare experiences for most children in the United States are composed of health maintenance services. As such, measuring the quality of health maintenance, also known as well-child care, is a salient way to measure pediatric healthcare quality.^{20, 21}

Process measures, measures that collect data on what happens during the health care provider-patient visit, may be the best manner of assessing quality.²² Researchers have traditionally used process measures such as immunization rates and rate of physician visits to document quality in well-child care. Because these measures do not inform the broad range of recommended preventive and developmental services, more inclusive process measures have been developed and used in large, national studies.²⁰ Since neither claims data nor medical records can adequately describe the health promotion that occurs in health maintenance visits, parent surveys may be the best method for determining the nature of these visits.²¹

As young children depend on their parents for healthcare services, we hypothesized that low parental literacy would be associated with poor well-child healthcare. We aimed to determine the nature of the relationship between parental literacy and the quality of well-child care.

METHODS

Setting, Recruitment and Participants

Our design was a cross-sectional survey using face-to-face interviews of the child's caregiver in the pediatric resident clinic at the University of North Carolina at Chapel Hill. The clinic has approximately 10,000 visits per year, about half of which are well-child. Approximately half of the children are African-American, the majority receive Medicaid or the state Children's Health Insurance Plan (SCHIP) and of the parents, 75% have graduated high school.

Each morning, our trained research assistant used the clinic's computer-generated schedule to identify potential participants. She recruited and obtained informed consent prior to the office visit and interviewed the participant after the visit. We conducted interviews

between January 2004 and March 2005. All caregivers were eligible if their child was between the ages of 12 and 48 months and had had at least one prior well-child visit at the clinic. Additionally, the caregiver had to be at least 18 years old and English-speaking.

Our trained research assistant explained to potential participants that she did not work for the clinic and that answers would be confidential. She explained that the goal of the study was to improve care in the clinic; she did not mention literacy while recruiting. In order to remove the bias of parental literacy, the research assistant read every question out loud. The University of North Carolina Institutional Review Board approved the study protocol.

Measures

<u>Parental Literacy</u>: The Rapid Estimate of Adult Literacy in Medicine (REALM) is a three-minute screening instrument used to identify people who have difficulty reading. The test is scored on the number of words pronounced correctly such that a score of 0-18 correlates to a 3rd grade reading level or below, 19-44 correlates to a 4th-6th grade reading level, 45-60 correlates to a 7th-8th grade reading level, and 61-66 correlates to a 9th grade reading level or above. The instrument is

well correlated with well-established reading comprehension instruments such as the WRAT-R.²³

<u>Quality of Care</u>: We used subscales of the Promoting Healthy Development Survey (PHDS), a standardized, well-validated 52-item parent survey designed to measure well-child quality of care.²⁴ The PHDS is the only established quality measure that specifically targets the quality of well-child healthcare for infants and preschoolers.²⁵ We used the subscales of the survey that measure the quality of health promotion and the quantity of health promotion messages.

The first two subscales, 1) family-centered care and 2) helpfulness/confidence-building, concern the quality of the health promotion regarding provider-parent relationships. Examples of topics covered in family-centered care are a) if the provider takes time to understand child's specific needs, and b) if the provider respects the parent's expertise. The response set is a 4-point scale of never, sometimes, usually, always. Examples of topics covered in helpfulness/confidence-building are a) if the provider helped the parent address her own needs while addressing those of the child, and b) if the provider helped the parent understand the child's behavior. The

helpfulness response set was a 5-point scale of very helpful, helpful, somewhat helpful, not at all helpful, we did not discuss. The confidence-building response set was a 4-point scale of "I feel... a lot more confident, a little more confident, not more or less confident, less confident."

The next two subscales, 3) family well-being and 4) anticipatory guidance, concern the quantity of health promotion messages: the content of the discussions within the well-child visit. Examples of topics covered in family well-being are a) if the provider discussed if the parent felt depressed, and b) if the provider discussed if the parent felt depressed, and b) if the provider discussed if the parent felt safe at home. The response set was: yes, no. Examples of topics covered in anticipatory guidance are a) if the provider discussed the child's growth and development, and b) if the provider discussed limit-setting techniques. The response set was a 4-point scale of "Yes, and all my questions were answered; Yes, but my questions were not completely answered; No, but I wish we had discussed; or No, but I already had information on this topic and did not need to discuss it anymore."

Statistical Analysis

We defined low literacy as a score below 61 (or below a 9th grade reading level) on the REALM and dichotomized the instrument between 8th and 9th grade. We chose to dichotomize at that point because, according to the instrument developers, at a reading level of eighth grade and below the patient "may struggle with most ... patient education materials."²³ Although our research question was not specifically related to the respondent's ability to read patient education materials, we thought this a good proxy for general comprehension. For our quality instrument, as recommended by the instrument developers, we analyzed the results of each subscale distinctly.^{20, 24} For the family-centered care subscale there were 8 questions; we calculated the percent of parents who gave a positive response (e.g., responded "always" or "usually") to every question within the subscale. We combined the 3 questions of the helpfulness subscale with the 4 questions of the confidence-building subscale and then dichotomized the answers into positive and negative responses. We then calculated the percent of parents who gave a positive response to every question within the subscale. For the 10 questions in the family well-being subscale, we assessed the percent of topics discussed. For the 33 questions in the anticipatory guidance subscale we assessed the

percent of topics for which the parent had her informational needs met for age-relevant topics. Having her informational needs met means the parent answered either "Yes, and all my questions were answered" or "No, but I already had information on this topic and did not need to discuss it anymore."

We then assessed the bivariate relationships between literacy and each of the four quality subscales. We assessed the bivariate relationship between reported highest grade completed and lowliteracy. We created 4 categories of highest grade completed: 8th-11th grade, 12th grade, and 13-21 years of education. We assessed the percent of low-literacy respondents within each of these three categories. We used chi square analysis for categorical variables and t-tests for continuous variables.

In our multivariable analysis we created four regression models to examine the relationship between our independent variable, literacy, and our four outcome variables, the score on each of the four quality subscales. To assess whether there were any characteristics of our sample that might confound the relationship between low literacy and each of the outcomes, we used bivariate analyses to compare low

literacy to each of the candidate covariates: age of parent, age of the child, gender of parent, race, marital status, whether the parents were living together, family income, and payment source. Candidate covariates were retained in our final model only if they affected the relationship between literacy and any of the quality outcomes.

Finally, to answer those who would argue that literacy as an independent variable is no more precise in predicting well-child quality than other, more commonly obtained individual characteristics, we performed multivariable analysis using these other characteristics as independent variables and the quality subscales as our dependent variables. Specifically, we created four models for each of the six family characteristics (gender, race, parents living together, source of payment, family income and education) to see if they would act as predictors of quality. We conducted data analyses using Stata 8.0 (College Station, Texas).

RESULTS

During the study period 250 adults meeting inclusion criteria were approached and 150 (60%) agreed to participate. Our respondents were 86% female and 80% of them were the child's mother (Table 1).

The mean age of the respondent was 30 years with a range of 18-64 years, 41% were white, 56% were African American, and 9% were Latino/Hispanic. Fifty-nine percent of the respondents reported that the child's mother lives with the child's father and 46% of the respondents were married. The payment source was 68% Medicaid and 49% had a family income of \$20,000 or less. The child's mean age was 21 months with a range of 12-48 months.

Eighty-six percent of respondents graduated high school and the mean REALM score was 60/66 with a range of 16/66 to 66/66 (Table 1). The highest grade completed by the respondent ranged from 8 to 21 years (Table 2). Fourteen percent of the sample reported that they did not complete high school. Thirty-four percent scored below a 9th grade reading level (low-literacy). In assessing the bivariate association between highest grade completed and low-literacy, we found that for individuals reporting they did not complete high school (n=21), 67% had low-literacy; for individuals reporting that they completed 12th grade and no more (n=60), 40% had low-literacy; for individuals who completed between 13 and 16 years of education (n=59), 20% had low-literacy; and for individuals who completed 17 or greater years of

education (n=10), 2% had low-literacy. These data show that as the highest grade completed increased, the percent of low-literacy respondents decreased. This data also show, however, that within every highest grade completed category, there are respondents with low-literacy.

We then assessed the bivariate relationships between family characteristics and low literacy (Table 1). We found the respondents in our low literacy group were more likely to be female, African American, to have parents live apart, receiving Medicaid, to have a family income less than \$20,000 a year, and to have not graduated from high school.

In our bivariate analysis comparing literacy and quality of care, we found that parents with low-literacy were more likely than those with normal or high literacy to report family centered care (55% versus 27%, p=0.001), and helpfulness and confidence (84% versus 56%, p<0.001) (Figure 1). There was no difference, by literacy level, in the mean percent of family well-being topics discussed or the mean percent of anticipatory guidance topics for which the parents had their informational needs met.

We then created four models, one for each of the quality subscales. We included as confounders each variable where we demonstrated a difference in the bivariate analysis. Ultimately, when we adjusted for confounders the associations we found in the bivariate analysis did not change: those with low literacy reported greater family centered care and helpfulness/confidence and there was no difference, by literacy, in the family well-being topics discussed or the anticipatory guidance topics for which they had their informational needs met.

The results of the logistic regression models for the six family characteristics (race, whether the parents live together, receipt of Medicaid, income less than \$20,000, and high school graduation status) showed no difference for any of the quality scores.

CONCLUSION

Measuring quality of care in children is difficult. It is difficult because bad outcomes are rare, because normal health and development in a child is defined by change, because developmental outcomes from poor quality of care might not manifest themselves during childhood, and because the health of a child may be as dependent on community

resources—such as school and day care—as it is on the healthcare system.^{4, 21} Measuring quality is, however, necessary for improving quality of care. In our study we used parental report of process measures to report quality of care.

Respondents with low-literacy were more likely to report that the health care providers from their child's well-child visit were family centered, helpful, and that the information they received from them improved their confidence in parenting. These same low-literacy parents did not, however, report that their health care providers had more discussions with them about topics related to family well-being or that they had their informational needs met more often for topics of anticipatory guidance.

Thus, regarding relationships with their health care providers, the lowliteracy respondents reported higher quality than the normal/high literacy group. Regarding recollection of information discussed, there was no difference in quality by literacy level.

As these results are different than our hypothesis, where we proposed that those with low-literacy would report lower quality of care, we need

to examine our results critically. Our literacy instrument is wellvalidated and generally administered in the manner in which we did it. Our quality instrument is also well-validated. Whereas our research assistant was face-to-face with the respondent and read the questions out loud to the respondents, the instrument's use in other studies has been a self-administered questionnaire or a telephone interview.^{20, 24} This may have increased the likelihood that our respondents would give a socially acceptable answer, and be less critical of the quality of the well-child visit, but we expect that this would have affected respondents of all literacy levels.

In other studies, when years of education of the respondent was used as an independent variable and the same quality subscales as dependent variables, there were no differences by education.^{24, 26} We were not deterred by this in designing our study as there is ample evidence that measuring literacy is different than measuring education: self-report of number of years of school completed may be up to five years higher than reading ability and up to 20% of those who graduate high school may have marginal literacy skills.²⁷⁻³⁰ There is evidence that literacy is more closely associated with health outcomes than is

years of education.³¹ In our study, we found similar results: in our bivariate analysis we found that there were respondents with lowliteracy in each of the categories describing highest grade completed. Thus, that we found no difference in quality subscale scores in our multivariable analysis, when we used high school graduation as the independent variable and we did find differences when we used literacy level as the independent variable is not surprising.

In rejecting our hypothesis we have considered potential mechanisms for our results. One mechanism for the difference in provider-parent relationships between low and high literacy groups might be that parents with low-literacy may have lower expectations regarding relationships with their healthcare provider. The low literacy families may not be activated to think about their needs or desires prior to the well-child appointment. They may come into the appointment with few preconceived notions and are therefore very accepting of the care that is delivered. Families with normal or high literacy may have more of an agenda for the well-child appointment and may be holding the healthcare provider up to a higher expectation.

Another potential mechanism is that pediatric residents may be more effective at relationship building with low-literacy families. Although physicians are generally unsuccessful in predicting which caretakers have low literacy,^{9, 32} other characteristics associated with literacy in our study may function to alert physicians to increased potential need. This may be related to preconceived notions that doctors in training have about family characteristics.

Our study is limited in that it is a cross-sectional analysis that describes an association and not causality. Generalizability may be limited as it was a single institution study with doctors in training.

We believe the data argue for further study to assess the quality measures of provider-parent relationships and discussions by comparing parental report to other modes of measurement such as audiotape or videotape. For if our data are due to lowered expectations of parents with low literacy then we may need to reexamine our measurement of quality of care. If, on the other hand, our data show a true phenomenon then we may need to understand and harness the relationship-building success of physicians-in-training working with low literacy parents.

Table 1.	Family	Characteristics	and Lite	eracy
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	All Respondents	Low literacy	High/Normal	p-value
	(N=150)	(n= 51)	Literacy (n=99)	
Respondent gender	86	94	82	0.04
(% female)				
Respondent relationship	80	84	78	0.34
(% mother)				
Respondent mean age	30.2 (8.2)	29.8 (8.9)	30.6 (7.8)	0.56
(standard deviation)				
(years)				

	All Respondents	Low literacy	High/Normal	p-value
	(N=150)	(n= 51)	Literacy (n=99)	
Race (% African	56	69	49	0.025
American)				
Ethnicity (% Latino)	9	6	10	0.38
Parents live together (%)	59	47	65	0.038
Married (%)	46	37	51	0.12
Source of payment is	68	82	63	0.013
Medicaid (%)				
Family income <=\$20,000	49	65	40	0.005
(%)				
Child mean age (standard	21.3 (8.8)	21.7 (9.4)	21.2 (8.5)	0.74
deviation) (months)				

Table 1. Family Characteristics and Literacy (continued)

	All Respondents	Low literacy	High/Normal	p-value	
	(N=150)	(n= 51)	Literacy (n=99)		
High school graduate (%)	86	73	93	0.001	
Mean REALM score	60.1 (8.1)	52.4 (9.9)	64.2 (1.4)	<0.001	
(standard deviation)					

Table 1. Family Characteristics and Literacy (continued)

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Table 2. Association between highest grade completed and low-literacy (N=150)

Highest	Grade Completed	Percent Low Literacy		
(n, % of	total)			
8-11	(21, 14%)	67%		
12	(60, 41%)	40%		
13-16	(59, 40%)	20%		
17-21	(10, 7%)	2%		
Total	(150, 100%)	34%		

	Family Centered Care (%)	p- value	Helpfulness & Confidence (%)	p- value	Family Well- Being (%)	p- value	Anticipatory Guidance (%)	p- value
Race African- American Other	35 38	0.75	65 65	0.75	45 56	0.06	84 82	0.62
Parents live Together Apart	37 35	0.88	62 72	0.23	49 51	0.76	85 81	0.35
Education HS grad < HS grad	35 41	0.63	64 78	0.27	50 50	0.99	83 83	0.98
Medicaid Yes No	40 27	0.20	65 69	0.72	52 44	0.19	84 81	0.84
Income <\$20,000 ≥\$20,000	42 31	0.26	70 63	0.43	50 50	0.99	83 83	0.96

Table 3. Quality of Care by Family Individual Characteristics (adjusted percents)*

* Adjusted percents based on the beta estimates from a logistic regression model for each outcome

Figure 1. Quality of Care by Literacy



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