

1 Are Parent Activation and Health Literacy Distinct Concepts? A Study in Low Income Urban Populations  
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## **Are Parent Activation and Health Literacy Distinct Concepts? A Study in Low Income Urban Populations**

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### **ABSTRACT**

Patient activation (the knowledge, confidence, willingness, and skills to manage one's healthcare) and health literacy have well-established associations with health and healthcare outcomes in adults. However, little is known about parent activation on behalf of children and its relation to health literacy. Our objective was to examine relations between parent activation, health literacy, and parent-provider relationship quality. We surveyed 316 Spanish- or English-speaking parents of publicly-insured patients of a general pediatrics clinic. Surveys included the Parent-Patient Activation Measure (P-PAM), the Newest Vital Sign (NVS), and parent-provider relationship measures. We used chi-square analyses and logistic regression to explore associations stratified by survey language. Spanish-speaking parents had significantly lower levels of both parent activation and health literacy compared with English-speaking parents ( $p < .001$ ). Parent activation was not associated with health literacy, suggesting that they are distinct concepts. Because parent activation is a more easily modifiable trait than health literacy, it may present an opportunity to improve outcomes in less health literate populations. We did not find expected associations between parent activation, health literacy and parent-provider relationship quality. Further study is needed to understand how parent activation relates to pediatric outcomes, and if it is an appropriate intervention target to address child healthcare disparities in populations with limited health literacy.

**Keywords:** patient activation; limited English proficiency; primary care; disparities

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### INTRODUCTION

There is growing emphasis on improving health and healthcare outcomes through increased engagement of patients in their healthcare. Healthcare activation, or individual-level patient engagement, is defined as “the knowledge, confidence, willingness, and skills to manage one’s health and healthcare” (Hibbard, Mahoney, Stockard, & Tusler, 2005). Studies in adults have found that those who are more activated have better health and healthcare outcomes including fewer hospitalizations, less emergency department utilization, reduced healthcare costs, and better disease outcomes (Greene, Hibbard, Sacks, Overton, & Parrotta, 2015; Marshall et al., 2013). Healthcare activation is thought to be modifiable; several adult intervention studies aimed at increasing activation have demonstrated improvements in health and healthcare quality (Greene et al., 2015). Based on these findings, there is growing interest in healthcare activation as a mediator of health outcomes, particularly in populations that face healthcare disparities. There is currently little information, however, on parent healthcare activation on behalf of children (“parent activation”), and its relation to pediatric health and healthcare outcomes.

Parent activation and health literacy may both affect pediatric healthcare outcomes, but the association between parent activation and health literacy is not known. A parent’s knowledge, confidence, willingness and skills to manage their child’s healthcare intuitively appears related to their ability to understand healthcare-related information. However, the limited evidence in adults has found weak to no associations between health literacy and healthcare activation, suggesting they may be distinct concepts (Greene, Hibbard, & Tusler, 2005; Hibbard, Peters, Dixon, & Tusler, 2007; Smith, Curtis, Wardle, von Wagner, & Wolf, 2013). Limited parent health literacy is associated with worse child health and healthcare outcomes including greater emergency department utilization and hospitalizations (DeWalt, Dilling, Rosenthal, & Pignone, 2007; Morrison, Myrvik, Brousseau, Hoffmann, & Stanley, 2013; Ross, Frier, Kelnar, & Deary, 2001). Current pediatric health and healthcare disparities in low-income families are in part attributed to low parent health literacy, but may also stem from low parent activation. Understanding the association of these two constructs may offer additional insight into interventions to address healthcare disparities.

#### Conceptual Framework

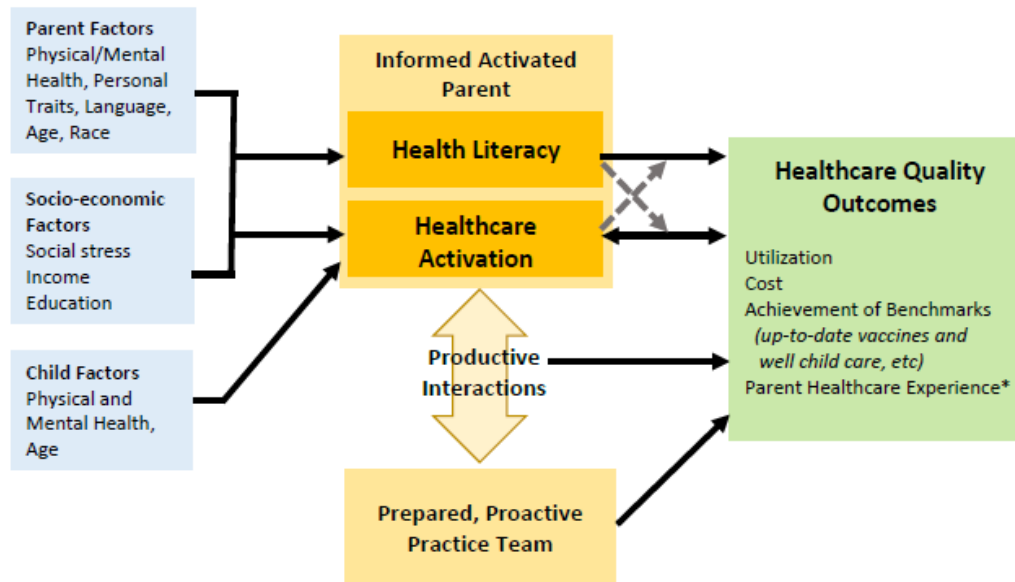
As the relations between parent activation, parent health literacy, and pediatric healthcare outcomes to our knowledge have not been collectively studied, we first developed a conceptual framework (Figure 1). We elected to center our framework on the widely accepted Chronic Care Model’s elements of productive interactions between an “informed, activated patient” and a prepared, proactive practice team given the similarities between effective chronic care and medical home-based pediatric primary care (Bodenheimer & Wagner, 2002; Medical Home Initiatives for Children With Special Needs Project Advisory Committee & American Academy of Pediatrics., 2002). Our framework was influenced by the model by Pennarola et al. relating parent and child traits to parent activation among parents of chronically ill children (Pennarola et al., 2012). Each pathway in our framework is informed by both adult and pediatric studies due to limited pediatric literature on activation (Alexander, Hearld, Mittler, & Harvey, 2012; Chari, Warsh, Ketterer, Hossain, & Sharif, 2014; DeWalt & Hink, 2009; Greene et al., 2015; Nijman, Hendriks, Brabers, de Jong, & Rademakers, 2014; Pennarola et al., 2012; Sanders, Federico, Klass, Abrams, & Dreyer, 2009; Yin et al., 2009). Parent activation and health literacy may affect pediatric health in

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part through enabling parents and physicians to interact effectively; thus, we selected parent-provider relationship quality as an outcome (Bodenheimer & Wagner, 2002).

**Figure 1.** Conceptual Framework.



\*Includes quality parent-provider relationships measured in this study by continuity of care and parent experience with provider communication

## METHODS

### Study Setting and Participants

From September 2014 through February 2015, we conducted a cross-sectional study in a convenience sample of parents from an urban, academic pediatric clinic. The clinic averages 11,000 visits annually, primarily with publicly-insured children. There are 26 clinic providers including board-certified pediatricians, residents, and a nurse practitioner, nearly all of whom are Spanish-language qualified for healthcare communication as assessed by the health system's bilingual staff policy.

Participants included parents or legal guardians above the age of 18 with a preferred healthcare language of either English or Spanish (hereafter referred to as "English-speaking parents" or "Spanish-speaking parents"). Additional inclusion criteria were child age of 6 months to 5 years, public health insurance, and at least 6 months of being a clinic patient. Participants provided informed consent after a research assistant read the consent form to them, and they were given \$10 remuneration. The Institutional Review Board at Johns Hopkins Medicine approved the study.

### Survey Administration

Trained research assistants proficient in both English and Spanish screened parents waiting during regular clinic hours and administered the survey according to preferred healthcare language. The default mode of survey administration was oral because of limited literacy among many clinic

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parents. 21% of parents elected to read the English or Spanish survey independently. Survey responses were captured during survey administration using REDCap (Research Electronic Database Capture) software on a touchscreen computer (Harris et al., 2009). Parents were asked to consider only one of their children in the specified age range when responding to survey questions. For parents with more than one eligible child, research assistants selected the child with an appointment that day to be the index patient. If either multiple or no eligible children had appointments on a given day, research assistants selected a child at random.

##### Survey Measures

*Demographics.* Parent and child information included age, gender, race/ethnicity, country of origin, and health status, as well as parent education. Family information included household income and number of children. English proficiency was assessed using the US Census Bureau question “How well do you speak English?” to which the response “very well” was interpreted as English proficient whereas “well,” “not well,” or “not at all” indicated limited English proficiency (U.S. Census Bureau, 2003). Foreign-born participants also reported years of residence in the United States. Children were classified as having a chronic health condition if any of the following were documented in their electronic medical record in the past 12 months (based on definitions of common chronic health conditions in the literature): asthma, prematurity with gestational age <35 weeks, developmental disorder or delay (autism or similar), congenital heart disease, Trisomy 21, chronic kidney disease, musculoskeletal malformations or ocular disorders (Fiks, Hunter, Localio, Grundmeier, & Alessandrini, 2008).

*Explanatory Measures: Parent Activation and Health Literacy.* The Parent Patient Activation Measure (P-PAM) was designed to evaluate parents’ knowledge, skills and confidence in managing their child’s health and healthcare. Insignia Health created the P-PAM by adapting the well-validated Patient Activation Measure (PAM) for use in pediatric settings, and it was used with their permission (Insignia Health, 2011). The P-PAM, similar to the PAM, consists of 13 declarative statements. Response options are on a four-point Likert scale ranging from disagree strongly to agree strongly, without a neutral option. Sample items include: “When all is said and done, I am the person who is responsible for taking care of my child’s health” and “I am confident I can tell a doctor concerns I have about my child’s health, even when he or she does not ask.” P-PAM responses are converted to activation scores (0-100) and levels (1-4) using the same methodology as the PAM. Higher scores and levels represent higher activation. Both English and Spanish P-PAM versions have acceptable psychometric properties; additional information about survey content and administration and P-PAM measure characteristics is reported elsewhere (DeCamp et al., 2016).

Health literacy was assessed using the well-validated Newest Vital Sign (NVS, scored 0-6) measure in English or Spanish (Weiss, Mays, Castro, & Hale, 2005). The NVS requires participants to respond to six questions based on a nutrition label, and they are awarded a point for each correct answer. A score of 0-1 represents a “high likelihood of limited literacy,” 2-3 represents “possibility of limited literacy,” and 4-6 represents “adequate literacy.”

*Parent-Provider Relationship Outcomes: Continuity of Care, Communication Quality, and Provider Rating.* To measure provider continuity, we selected the COC developed by Bice and Boxerman because it has been used in prior studies to capture provider dispersion in pediatric settings (Bice & Boxerman, 1977; Jee & Cabana, 2006). The COC has a continuous range from 0

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to 1 (Equation 1). A COC of zero signifies no continuity, meaning that a different provider was seen for each visit. A COC of one indicates that the same provider was seen for every visit. We calculated the COC based on well-child, acute, and follow-up clinic visits in the 12 months prior to the survey date. At least 3 visits are required to calculate the COC; children with less than 3 visits in the past year were excluded from the COC analysis.

**Equation 1.** Continuity of Care.

$$\text{COC} = \frac{\sum_{j=1}^s n_j^2 - n}{n(n-1)}$$

$n$  = total number of visits

$n_j$  = number of visits to provider  $j$

$s$  = total number of providers

Parents assessed their provider and provider communication quality using five questions from the well-validated Consumer Assessment of Healthcare Providers and Systems (CAHPS) Clinician and Group 12-Month Survey (Agency for Healthcare Research and Quality). Parents responded to provider communication quality questions on a 4 point scale (never, sometimes, usually, always) and rated their provider on a scale from 0 (“Worst provider possible”) to 10 (“Best provider possible”). Responses were dichotomized using a top box system of “always” or “10” versus other responses, respectively (American Institutes for Research, 2010).

### Data Analysis

We conducted analyses among all respondents and stratified by survey language. Parent activation levels were dichotomized as “high” (Level 4) and “low” (Levels 1-3) due to positive skew of PPAM scores. Based on the preponderance of participants with low scores on our health literacy measure, we elected to dichotomize health literacy levels as limited (NVS 0-1) and adequate/marginal (NVS 2-6). We first tested for an association between parent activation level and health literacy level using chi-square analysis. Subsequent analyses tested for associations between the explanatory variables and parent-provider relationship measures (COC, provider communication quality and provider rating) adjusting for baseline parent and child characteristics. All statistical analyses were conducted using Stata/SE Version 13.

## **RESULTS**

### Child and Family Characteristics

A total of 316 surveys were completed, of which 68% were conducted in Spanish. Eighty percent of approached parents agreed to be screened, and 92% of eligible parents completed the survey. Table 1 presents characteristics of the parent, family, and index child stratified by language. Nearly all Spanish-speaking parents were foreign-born, and 23% of English-speaking parents were foreign-born. All index children were US-born. Over 60% of both groups had annual household incomes below \$30,000. Spanish-speaking parents had lower educational attainment than English-speaking parents; 73% reported less than a high school education versus 27%, respectively ( $p < .001$ ). Fewer children of Spanish-speaking versus English-speaking parents had a documented chronic health condition (21% vs. 29%, respectively;  $p = .003$ ).

### Explanatory Variables: Parent Activation and Health Literacy

Parent activation and health literacy were not associated, among respondents as a whole and when stratified by language. Spanish-speaking parents had lower activation mean scores and

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levels than their English-speaking counterparts, as seen in Table 1 ( $p < .001$ ). Health literacy was also significantly lower among Spanish-speaking parents, 57% of whom had limited health literacy compared with 23% of English-speaking parents ( $p < .001$ ). Within each language group, however, there was no significant association between parent activation and health literacy. The lack of relation between activation and health literacy is evident when looking at the distribution of parent activation and health literacy in Table 2. For Spanish-speaking parents, about 50-60% had low activation regardless of health literacy scores. Similarly, for English-speaking parents, 35-40% had low activation regardless of health literacy scores.

Table 3 displays bivariate analyses of sociodemographic characteristics with parent activation and health literacy. For Spanish-speaking parents, low health literacy was associated with having less than a high school education ( $p = .001$ ), child age under 12 months ( $p = .007$ ), and lack of a pediatric chronic health condition ( $p = .006$ ). In English-speaking parents, low health literacy was associated with parents being foreign-born ( $p = .002$ ) and annual household incomes under \$20,000 ( $p = .021$ ). The only significant associations between parent activation and family characteristics were with multiple children in the household ( $p = .017$ ) and child health status ( $p = .025$ ) for Spanish-speaking parents.

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**Table 1.** Characteristics of 316 caregivers & children, presented as mean (SD) or n (%)

	English <sup>†</sup> n = 102	Spanish <sup>†</sup> n = 214	p-value <sup>‡</sup>
<b>Parent and Child Characteristics</b>			
<b>Parent age (years)</b>	27.8 (7.7)	29.4 (5.7)	.065
<b>Parent female gender</b>	87 (86%)	204 (95%)	<b>.004</b>
<b>Parent race/ethnicity</b>			
Non-Hispanic Black	41 (40%)	0 (0%)	<b>&lt;.001</b>
Non-Hispanic White	15 (15%)	0 (0%)	
Hispanic/Latino	24 (24%)	210 (99%)	
Other/mixed race	22 (22%)	3 (1%)	
<b>Foreign-born parents</b>	23 (23%)	211 (99%)	<b>&lt;.001</b>
<b>Annual family income</b>			
<\$20,000	46 (45%)	101 (47%)	<b>&lt;.001</b>
\$20,000-30,000	18 (18%)	35 (16%)	
>\$30,000	24 (24%)	14 (7%)	
Did not know/Refused	14 (14%)	64 (30%)	
<b>Parent education</b>			
Less than high school	28 (27%)	157 (73%)	<b>&lt;.001</b>
High school or GED	41 (40%)	44 (21%)	
Some post-secondary	33 (32%)	13 (6%)	
<b>Parent limited English proficiency</b>	13 (13%)	209 (98%)	<b>&lt;.001</b>
<b>Number of children in household</b>	2.0 (1.2)	2.0 (1.0)	.421
<b>Child age (months)</b>	29.3 (18.8)	27.6 (17.1)	.420
<b>Presence of child chronic condition(s)*</b>	30 (29%)	44 (21%)	<b>.003</b>
<b>Reported health status of child</b>			
Excellent	54 (53%)	89 (42%)	<b>.004</b>
Very good	30 (29%)	48 (22%)	
Good/Fair	18 (18%)	77 (36%)	
<b>Key Explanatory Variables</b>			
<b>Parent Health Literacy (NVS score)</b>			
Limited literacy (0-1)	23 (23%)	122 (57%)	<b>&lt;.001</b>
Adequate/marginal literacy (2-6)	79 (77%)	92 (43%)	
<b>Parent Activation</b>			
PPAM Score: Mean (SD)	79.1 (16.2)	70.7 (17.9)	<b>&lt;.001</b>
PPAM Levels: n (%)			
“Low” (Level 1-3)	39 (38%)	121 (57%)	<b>&lt;.001</b>
“High” (Level 4)	63 (62%)	93 (43%)	

<sup>†</sup> Language of survey completion, based on parental report of preferred healthcare language

<sup>‡</sup> p-values for t-test (continuous data), rank sum (skewed data) and chi-squared (categorical data)

\* Obtained from EMR, includes: asthma, prematurity, developmental disorder or delay, congenital heart disease, Trisomy 21, chronic kidney disease, musculoskeletal or ocular disorders

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**Table 2.** Distribution of parents among parent activation and health literacy subsets. Data are presented as n (% of literacy subset, stratified by language group).

	English (n=102)			Spanish (n=214)		
	Low Activation	High Activation	p-value	Low Activation	High Activation	p-value
Limited Literacy	8 (35%)	15 (65%)	.70	73 (60%)	49 (40%)	.26
Adequate/Marginal Literacy	31 (40%)	48 (60%)		48 (52%)	44 (48%)	

**Table 3:** Parent and child characteristics within parent activation and health literacy categories. Data are presented as % of parents within each category of parent activation or health literacy for the characteristic.

Parent and Child Characteristics	Explanatory Variables							
	English (n=102)				Spanish (n=214)			
	Parent Activation		Health Literacy		Parent Activation		Health Literacy	
	Low	High	Limited	Adequate Marginal	Low	High	Limited	Adequate Marginal
Parent Education <High School	77%	70%	35%	25%	76%	70%	<b>82%**</b>	<b>62%**</b>
Annual Family Income <\$20,000	48%	55%	<b>65%*</b>	<b>39%*</b>	35%	29%	28%	37%
>1 Child in Household	64%	57%	70%	57%	<b>74%*</b>	<b>58%*</b>	68%	65%
Child Age <12 months	74%	83%	22%	20%	23%	17%	<b>27%**</b>	<b>12%**</b>
≥1 Child Health Condition	28%	30%	35%	28%	21%	20%	<b>14%**</b>	<b>29%**</b>
Health Status of Child <“Excellent”	59%	40%	52%	46%	<b>66%*</b>	<b>49%*</b>	61%	54%
Foreign-born Parent	28%	19%	<b>37%**</b>	<b>17%**</b>	--- (Nearly all foreign born)			
Parent’s Years in US ≤ 8 (the median)	--- (Small cell size)				49%	47%	56%	47%
Parent Race/Ethnicity								
Non-Hispanic White	23%	17%	9%	23%	---			
Non-Hispanic Black	31%	46%	52%	37%	(Limited race specification beyond Latino ethnicity)			
Hispanic/Latino	23%	13%	9%	19%				
Other/Mixed race	23%	34%	30%	21%				

\*p<.05 significant difference *between* categories of parent activation or health literacy for the characteristic, all significant values are also bolded

\*\*p<.01 significant difference *between* categories of parent activation or health literacy for the characteristic, all significant values are also bolded



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**Table 4.** Odds ratios for parent-provider relationship outcomes by parent activation and health literacy (HL) stratified by language (unadjusted, or adjusted odds ratio displayed if significant).

Odds Ratios by Explanatory Variables [95% CI]						
		English (n=102)		Spanish (n=214)		
Parent-Provider Relationship Outcomes	%	High Parent Activation (Ref: Low Activation)	Adequate/Marginal HL (Ref: Limited HL)	%	High Parent Activation (Ref: Low Activation)	Adequate/Marginal HL (Ref: Limited HL)
<b>High Continuity of Care (top tertile, COC 0.5-1)<sup>†</sup></b>	30%	0.92 [0.34, 2.48]	<b>0.17*</b> <b>[0.05, 0.54]</b>	31%	0.82 [0.43, 1.55]	0.92 [0.34, 2.48]
<b>Experience with Provider Communication</b>						
Always explained clearly	<b>91%<sup>‡</sup></b>	0.79 [0.19, 3.37]	0.98 [0.19, 5.07]	<b>81%<sup>‡</sup></b>	1.19 [0.59, 2.40]	0.62 [0.31, 1.24]
Always listened carefully	90%	2.68 [0.71, 10.19]	0.35 [0.04, 2.95]	93%	0.44 [0.15, 1.25]	0.57 [0.20, 1.58]
Always showed respect	94%	0.80 [0.14, 4.57]	1.79 [0.31, 10.43]	96%	0.97 [0.25, 3.71]	0.36 [0.09, 1.50]
Always spent enough time	<b>86%<sup>‡</sup></b>	1.25 [0.40, 3.92]	0.93 [0.24, 3.65]	<b>73%<sup>‡</sup></b>	1.67 [0.89, 3.13]	0.56 [0.30, 1.03]
Rated Provider 10/10	67%	1.74 [0.75, 4.03]	0.48 [0.16, 1.43]	76%	2.04 [1.05, 3.96]	0.62 [0.33, 1.16]
Responded “always” to all 4 domains and rated provider 10/10	62%	1.71 [0.76, 3.89]	0.64 [0.24, 1.74]	53%	1.33 [0.77, 2.28]	<b>0.55**</b> <b>[0.32, 0.95]</b>

<sup>†</sup>n=258 for COC (English n=76; Spanish n=182) due to  $\geq 3$  clinic visits required to calculate COC

<sup>‡</sup>significant difference in outcome ( $p < .05$ ) between English and Spanish language groups

\* $p < .05$  even when adjusted for significant demographic covariates in English language group:

parent income and parent US nativity

\*\* $p < .05$  even when adjusted for significant demographic covariates in Spanish language group:

parent education, number of children in household, child age, presence of child chronic condition, and reported health status of child

### Parent-Provider Relationship Outcomes

There were few associations between parent activation, health literacy, and parent-provider relationship outcomes (Table 4). In unadjusted analyses, Spanish-speaking parents with high activation had twice the odds of rating their provider 10/10 than those with low activation in (OR=2.04, 95% CI [1.05, 3.96]  $p = .036$ ), although this was not significant in the adjusted model. In both unadjusted and adjusted models, English-speaking parents with adequate/marginal health literacy were significantly less likely to experience high continuity of care than those with limited health literacy (OR=0.17, 95% CI [0.05, 0.54],  $p = .003$ ). In both unadjusted and adjusted models, Spanish-speaking parents with adequate/marginal health literacy had half the odds of a top rating for provider communication quality compared with Spanish-speaking parents with limited health literacy (OR=0.55, 95% CI [0.32, 0.95]  $p = .031$ ). Regression analyses without language

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stratification demonstrated no substantive differences. The parent-provider relationship outcomes were generally similar for both language groups (Table 4). Continuity of care was similar between language groups. Among provider communication measures, English-speaking parents more often reported that their provider “always” explained things clearly ( $p=.023$ ) and spent enough time with their child ( $p=.008$ ).

### DISCUSSION

In this sample of low income parents of publicly insured children, health literacy and parent activation were not associated, indicating they may be distinct modifiers of healthcare quality outcomes. There were also no clear association patterns between these explanatory variables and patient-provider relationship outcomes. To our knowledge, the relations between parent activation, health literacy, continuity of care, and parent experience with provider communication have not been studied together in the pediatric setting.

While health literacy and activation appear to be separate constructs, in adults they have been associated with common predictors such as education, language, race, and income (Hibbard et al., 2008; Nijman et al., 2014; Yin et al., 2009). There is limited data in pediatrics on factors that contribute to parent activation. As seen in adults, higher activation and health literacy scores were significantly associated with English language preference (Alegría, Sribney, Perez, Laderman, & Keefe, 2009; Cunningham, Hibbard, & Gibbons, 2011). The relation between language and health literacy is well studied (Weiss et al., 2005). The association between language and parent activation is still being explored but is likely in part due to cultural differences; research shows that less-aculturated Latinos defer more often to physicians for decision making (DeCamp et al., 2016; López et al., 2014). In contrast to adult activation studies, we did not find associations between parent activation and education, race/ethnicity, or income. Our findings support those of another pediatric study by Pennarola et al. (2012) in which there also were no associations between parent activation and socioeconomic status or family characteristics. This lack of association could indicate that parent activation on behalf of children is a somewhat distinct concept from that of adult patient activation. Parent activation and how parents interpret P-PAM questions may differ from patient activation measured by the PAM given the different attitudes and responsibilities that surround caring for one’s child’s health versus one’s own (DeCamp et al., 2016). Considering the established associations between health literacy and socioeconomic status, the lack of association between parent activation and socioeconomic predictors supports the assertion that parent activation is determined by more or different predictors than health literacy.

Our findings agree with the absent or weak associations found between health literacy and patient activation in adults (Greene et al., 2005; Hibbard et al., 2007; Smith et al., 2013). Our results show that parents with adequate health literacy can have low activation, while parents with limited health literacy can have high activation. While health literacy and parent activation may share a “knowledge” component, the confidence and motivation of parents, or lack thereof, are not accounted for by health literacy measures. One adult study showed that health literacy and activation were not associated, and patients with low health literacy but high activation scores had better comprehension and quality decision-making compared to their less activated counterparts (Hibbard et al., 2007). This pattern suggests that activation may help low literacy populations compensate for literacy and numeracy skills and better navigate the healthcare system. Our study

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confirmed the lack of association between parent activation and health literacy in pediatrics, supporting their placement as separate parallel constructs in our conceptual framework.

We found few associations between parent activation, health literacy and parent-provider relationship outcomes. Continuity of care was significantly associated with health literacy only in the English-speaking group. English-speaking parents with adequate/marginal health literacy had lower continuity of care than those with limited health literacy. English-speaking parents with limited health literacy also had fewer visits to the clinic on average (data not shown). This may be in part because parents with limited health literacy sought less care or sought acute care elsewhere. Substantial research has demonstrated an association between low health literacy and increased emergency department use (Morrison et al., 2013). Use of the emergency department or an urgent care center for acute care would artificially inflate the COC as the child would have fewer acute visits to clinics. At the study site, consistent with parent preferences, timely access to acute care is prioritized over provider continuity (Zickafoose, DeCamp, & Prosser, 2015). The limitations of the COC may compromise our ability to detect an impact on the association between activation and healthcare seeking behaviors. The same relation between health literacy and COC may not have been seen in the Spanish-language group given the established difference in healthcare seeking behaviors in this group (Flores, Abreu, Olivar, & Kastner, 1998).

Parent experience with provider communication was also largely unrelated to parent activation and health literacy. In adults, both patient activation and health literacy are linked to improved patient experience with provider communication (Sanders et al., 2009; Alexander et al., 2012). Consistent with prior research, parents with adequate/marginal health literacy were less likely to rate their experience with provider communication at the highest level than parents with limited health literacy. Parents with higher health literacy may have different expectations and a higher threshold for what constitutes excellent provider communication (Sanders et al., 2009). We did not find any association between parent activation and provider communication quality. Based on adult literature and our conceptual model, we hypothesized that the most robust associations between parent activation and patient experience measures would be in the communication domains of the CAHPS. Parent activation may show stronger associations with other measures of communication quality, with other CAHPS domains such as access to care, or with measures of parent response to parent-providers interactions such as behavior change or medication/treatment plan adherence. As patient experience of care is a key component of the “Triple Aim” of healthcare, and as adult activation studies have shown associations with different patient experience measures, further study between parent activation and other aspects of parent experience is warranted.

When interpreting our findings, we must consider pertinent study limitations. First, the cross-sectional study design limits our ability to make conclusions on causation. Second, children of parents with the lowest activation and/or lowest health literacy may not have presented to clinic at all. The resulting selection bias would skew activation and/or literacy scores, precluding us from seeing certain associations in this sample. Given the positive skew of P-PAM scores compared to in adult studies, social desirability bias may also affect P-PAM scores more than PAM scores. Parents may be less willing to admit they face challenges in their child’s healthcare interactions than in their own. Alternatively, there are different attitudes and responsibilities that guide parental management of their child’s health versus their own. Exploration of how parents interpret P-PAM

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questions could better illuminate what drives the measure as well as the concept. Next, our study did not account for provider implicit bias or the presence of structural racism in health systems. Both of these factors may be unmeasured confounders that impact activation, patient/provider communication quality and healthcare outcomes. Prior research has demonstrated providers' implicit biases regarding patient characteristics, such as race, can adversely affect patient-provider communication (Cooper et al., 2012). Structural racism in healthcare systems may blunt the influence of individual patient activation on communication quality or healthcare outcomes in low-income or racial/ethnic minority patients. Further study is warranted to explore how provider implicit bias and structural racism in health systems may impact the proposed pathway between activation, health literacy, and healthcare outcomes. Finally, this was a single site study in which nearly all clinic providers have been qualified as proficient for healthcare communication in Spanish. This degree of parent-provider language concordance may limit the generalizability of our findings to settings where parents with limited health literacy face the added barrier of language discordance. Providers and staff in this clinic setting also have significant interest and expertise working with families with low general and health literacy, which may mitigate common barriers for these families.

With these limitations acknowledged, our study presents novel data about parent activation, health literacy, and parent-provider relationship quality in a diverse sample of low-income parents. With the rising interest in parent activation, it is critical to understand its relation to health literacy given its potential role to improve outcomes in vulnerable populations, such as those with limited health literacy. Future studies should examine the relation between parent activation and other health and healthcare outcomes to better understand the utility of parent activation as a target of interventions. A better understanding of the role of activation and other domains of parent engagement in child healthcare may shed light on new ways to achieve healthcare equity for underserved populations.

### **CONCLUSION**

Parent activation and health literacy were not associated in this low-income urban patient population. It is important to understand the relation between these concepts and their connection to health outcomes because parent activation is more easily modifiable than health literacy. Our study showed that they are distinct, which suggests that activation may present an opportunity to improve outcomes in limited health literate populations. Though our findings did not demonstrate a consistent association to the outcome of parent-provider relationship quality, the evidence in adult studies warrants further exploration of the association between parent activation and child health and healthcare outcomes.

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