Parental health literacy, barriers to care, and child hospital outcomes among hospitalized children

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A thesis

submitted in partial fulfillment of the

requirements for the degree of

Master of Public Health

University of Washington

2019

Committee:

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Program Authorized to Offer Degree:

Health Services

University of Washington

Abstract

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Objectives: Parents with low health literacy (HL) are less likely to participate in shared decision-making with their child's provider. We explored associations between parents' HL and barriers to participation and clinical outcomes. **Study design:** We conducted a prospective cohort study using secondary survey and administrative data at a large pediatric hospital from 10/2014 through 12/2015. Parents of children admitted to a medical or surgical service who completed a two-phase survey were included. We used linear and logistic regression to estimate associations between low HL and patient outcomes (length of stay, unplanned readmission) and five parent-reported barriers, adjusting for confounders. **Results:** Of eligible families, 10.7% (391) had low HL. Children of parents with low HL stayed in the hospital 0.18 days longer than children of parents with adequate HL (95% CI=0.027–0.310) but were not more likely to

experience unplanned readmission (OR=0.95; 95% CI=0.61–1.49). Parents with low HL had higher odds of cultural distance with their child's provider (OR=1.38; 95% CI=1.03–1.84). We found a possible association between low HL and system barriers (OR=1.33; 95% CI=0.95–1.86), physician distrust (OR=1.46; 95% CI=0.92–2.33), and better partnership (OR=0.65; 95% CI=0.40–1.06), though the magnitude remains uncertain. Low HL was not associated with distrust in the healthcare system after adjusting for covariates (OR=0.91; 95% CI=0.66–1.27).

Conclusions: HL was associated with longer length of stay and several parent-reported barriers to care. Strategies that better engage low-HL families could increase involvement in shared decision-making by reducing cultural distance, system barriers, and distrust, and might thereby reduce length of stay. However, HL is not the only (or most important) barrier families face.

Introduction

Background

Healthcare reform efforts in the United States have placed increased emphasis on quality of patient experience as a key measure of health system performance. In response to the Triple Aim, a framework emphasizing the goals of improved population health, improved quality of care, and reduced overall costs, health systems and policymakers are rapidly embracing new payment models and quality reporting tools that incentivize high-value, high-quality care.[1] Increasing patient involvement in shared decision-making is central to achieving the Triple Aim, but actively engaging patients in their care decisions remains a challenge.[2]

One factor that influences a patient's ability to participate in shared decision-making around their health care is health literacy, a key driver of health disparities in the United States.[3–5] The concept of health literacy has gained increasing attention as researchers and practitioners have acknowledged the role it plays in a patient's ability to understand their own health, navigate a complex health system, and participate actively in decisions around their care.[6,7] The Institute of Medicine defines health literacy as "the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[4,8] As of 2010, 90 million adults in the United States had low health literacy.[4] Low health literacy disproportionately impacts individuals who are low-income, have limited English proficiency (LEP), and who are racial and ethnic minorities, exacerbating existing health disparities.[9] Moreover, the implications of low health literacy are costly, accounting for between 7 and 17 percent of personal healthcare expenditures in the United States.[10]

In pediatric care, the health literacy of a parent, guardian or caregiver (henceforth, parent) can impact the care of a child. Parents with low health literacy are more likely to experience barriers to care for their child such as ability to reach a provider after hours.[11] They also report greater trust in their child's physician to make unilateral decisions, as well as poorer perceived partnership with their child's provider, perhaps due to difficulties accessing and understanding complex health information.[11] As a result, parents with low health literacy are less likely to participate in shared decision-making around their child's care.[11]

Because shared decision-making improves patient satisfaction and quality of care, pediatric patients whose families have low health literacy may be at increased risk of poor clinical outcomes such as longer hospital stays and preventable readmission.[11] Health systems

therefore have a vested interest in identifying families who struggle with health literacy and employing strategies to better engage them in their children's health care decisions. The Institute of Medicine has recommended that providers regularly screen patients for low health literacy and apply strategies to both improve individuals' health literacy and empower them to play an active role in their care decisions.[4]

While previous research has shown that parents with low health literacy report greater barriers to care, greater trust in their child's physician, and poorer partnership with their child's care team, little is known about how health literacy affects other aspects of the care experience such as cultural distance and trust in the health system as a whole. Cultural distance is a dynamic concept used to capture the level of concordance or discordance between a patient and their provider in terms of life experience, values, communication, and approach to problem-solving.[12] Trust in the health system is distinct from trust in physician or trust in an institution in that it measures an individual's trust in hospitals, clinics and health plans in general.[13]

Additionally, little is known about whether a parent's low health literacy impacts clinical outcomes such as length of hospital stay and unplanned readmissions, which previous research has shown are associated with low health literacy in adult patients.[14–16] This study aims to address these gaps in knowledge by describing the prevalence of low health literacy among parents of children hospitalized in a large pediatric hospital, and exploring clinical and personal factors associated with low health literacy in this setting.

Study Aims

The primary aim of the study is to evaluate the association between low parental health literacy and pediatric patient outcomes (length of stay and unplanned readmission within 30 days of discharge). We hypothesize that patients whose parents had low health literacy would experience longer average length of stay and greater odds of unplanned readmission within 30 days, compared to children whose parents had adequate[a] health literacy.

The secondary aim of the study is to evaluate the association between low health literacy and parent-reported barriers to high-quality care (distrust of the healthcare system, cultural

[a] The term "adequate" refers to individuals whose health literacy is high enough to allow them to effectively navigate the health system as it exists today and to understand their providers' explanations and care instructions. The responsibility to effectively serve families who have low health literacy rests with providers and the health system itself, and the terms "adequate" and "low" health literacy are not meant to place the burden of health literacy on parents and patients themselves.

distance, distrust of their child's physician, poor partnership with the care team, and the system as a barrier to care). We hypothesize that parents with low health literacy would report higher barriers to high-quality care, compared to parents with adequate health literacy.

Methods

In this prospective cohort study, we analyzed data from a survey of parents of hospitalized children at a large, free-standing pediatric hospital, and hospital administrative records from October 1, 2014 to December 31, 2015.

Study Setting & Population

We used secondary data from a large pediatric research hospital serving Seattle residents as well as families from the surrounding region of Washington, Alaska, Montana and Idaho.

Parents of children who were admitted to a medical or surgical service at the hospital were included. We excluded parents of children who were admitted for inpatient psychiatry, inpatient rehabilitation, bone marrow transplant, and scheduled chemotherapy, as their patterns of care were expected to differ significantly from the general patient population of the hospital. Families who had completed the survey within the past 2 months, whose children were immunocompromised and in strict isolation, and whose children had been admitted for suspected child abuse were not eligible for the survey.

Data Collection

Survey: We collected survey data to assess parents' health literacy, other potential social determinants of health, and barriers to high-quality care. Parents were surveyed from October 1, 2014 to December 31, 2015. While in the hospital, parents of hospitalized children were asked to participate in the study. The study consisted of telephone or web-based surveys, administered at two timepoints – one while in the hospital at some point within 72 hours of admission, and a separate discharge survey within 2 weeks of discharge. Parents were given the option of completing the web-based discharge survey independently or over the telephone with a research assistant. Surveys were available in both Spanish and English. For each hospitalized patient, only one parent was asked to complete the survey.

Administrative records: We used administrative records from the hospital's electronic health records system to assess length of stay and unplanned readmission within 30 days of

discharge, as well as confounding factors (age, parent-reported race/ethnicity, insurance type, preferred language for medical care, and medical complexity).

Definition of Variables

Predictor: Parent health literacy was our predictor variable. We assessed health literacy using the Single Item Literacy Screener (SILS), a validated and reliable measure of health literacy that asks "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?"[17] Parents could choose from five response options: *never, rarely, sometimes, often,* or *always*. The SILS performs well against direct tests of health literacy, including the Short Test of Functional Health Literacy in Adults (S-TOHFLA), the Rapid Estimate of Adult Literacy in Medicine (REALM), and the Pediatric Health Literacy Activities Test (PHLAT).[17–20] The one-question structure of the SILS allowed it to be seamlessly incorporated into existing surveys without placing undue burden on participants.

Parents completed the SILS as part of the initial survey, administered within 72 hours of admission. We classified parents as having *low health literacy* if they reported that they needed to have someone help them sometimes, often or always.[17] Parents who reported never or rarely needing help were classified as having an *adequate health literacy* score.

Outcomes: The primary aim focused on two outcomes: length of stay and unplanned readmission within 30 days. These variables were ascertained from hospital administrative records. Length of stay was defined as the number of days between admission and discharge, rounded to the nearest tenth of a day. We winsorised the length of stay variable at the 99th percentile to account for extreme outliers.[21] Unplanned readmission was defined as a readmission to the hospital that was not for a planned procedure. We used International Classification of Disease, 9th Revision (ICD-9) and ICD-10 procedure codes to identify readmissions that were unlikely to be related to a planned procedure using methods developed by Berry, et al.[22]

For the secondary aim, we focused on five parent-reported barriers to high-quality care: distrust of the healthcare system, cultural distance between parent and provider, distrust of child's physician, poor partnership with the care team, and the system itself as a barrier to care. We chose these outcomes for two reasons. First, previous research indicates that parents with low health literacy are more likely to experience access barriers such as trouble reaching

providers on nights and weekends and difficulty traveling to primary care.[11] We therefore wanted to explore more abstract individual-level barriers related to parents' perceptions of the healthcare system. Second, previous research indicates that parents with low health literacy are less likely to participate in shared decision-making with their child's care team, which may lead to disparities in quality and outcomes.[6,7,11] We chose to evaluate parents' sense of partnership, trust and cultural distance in order to better understand potential mechanisms behind the association between low health literacy and shared decision-making.

The survey items used to measure barriers to care are detailed in Appendix I. To assess distrust of the healthcare system, we used the Health Care System Distrust Scale,[23] which asks about perceptions of corruption, discrimination, and ethics within the healthcare system. To assess cultural distance we used the Cultural Distance Scale,[12] a 4-question scale that measures perceived similarity or difference in norms and values between parent and medical providers. Distrust of child's physician was assessed with the Wake Forest Physician Trust scale,[24] which measures patients' trust of the physicians providing their care. Poor partnership was assessed using the partnership-building subscale of the instrument to assess Parents Perceptions of Physicians' Communicative Behavior.[25] The system as a barrier was assessed using an item from the Barriers to Care Questionnaire,[26] which measures global perceived barriers to navigating the healthcare system.

These outcomes were assessed either as part of the initial survey that was administered within 72 hours of admission (distrust of system, cultural distance, barriers to care) or in the discharge survey that was administered within 2 weeks of discharge (distrust of physician, poor partnership). Each of these variables was assessed on a scale based on respondents' answers (details on the scale for each measure are outlined in Appendix I). A larger score on the scale indicated a higher degree of the issue (higher distrust, poorer partnership, greater barriers to care, etc.). Due to the positively skewed distribution of responses, we dichotomized each variable such that the top 33% of respondents were categorized as having a high score on the scale (i.e. high system distrust, high degree of cultural distance, high distrust in child's physician, poor partnership, and high degree of system-level barriers).[27] The bottom 66% of respondents were categorized has having a lower degree of each outcome. This allowed us to use a more meaningful and interpretable measure of each outcome.

Covariates: We selected confounders and covariates *a priori* based on previously published relationships.[11] These included patient insurance type (public or private/other), parent's likelihood to benefit from an interpreter (based on preferred language and level of English proficiency,[28] henceforth referred to as interpreter need), parent race/ethnicity (minority or non-minority), patient medical complexity (classified using the Pediatric Medical Complexity Algorithm[29]), and patient age.

Analysis

Administrative data was merged with survey data to create a single dataset. We excluded from the analysis families who did not complete the health literacy portion of the survey.

Primary Analysis: Given that length of stay is positively skewed, we used a generalized linear model with inverse Gaussian distribution to estimate the difference in length of stay associated with low parent health literacy, calculating both crude and adjusted associations. In our adjusted model we included patient age, insurance type, medical complexity, and parent interpreter need as covariates. We used a modified Park test[30] to confirm the appropriateness of the inverse Gaussian distribution for the model.

We used logistic regression to estimate crude and adjusted odds ratios (OR) and 95% confidence intervals (CI) for the association between low parent health literacy and unplanned readmission within 30 days. In our adjusted model we included patient age, insurance type, medical complexity, and parent interpreter need as covariates.

Secondary Analysis: For each of our secondary outcomes, we used logistic regression to estimate crude and adjusted odds ratios (OR) and 95% confidence intervals (CI) for the association between low parent health literacy and high parent-reported barriers.

For our analyses of system distrust and physician distrust, we adjusted for patient insurance type, race/ethnicity, medical complexity, and parent interpreter need. For our analysis of cultural distance, we adjusted for patient insurance type, race/ethnicity, and parent interpreter need. For our analyses of poor partnership and barriers to care, we adjusted for patient insurance type, medical complexity, and parent interpreter need.

Results

Characteristics of Study Sample

Of the 5,992 parents who were eligible to complete the survey, 3,660 (61.1%) completed the single item health literacy screening question. Of those parents, 3,568 (96.7%) completed at least one question about overall barriers to care (system distrust, cultural distance, distrust of physician, poor partnership with care team, or the system as a barrier to care) in the admission and/or discharge surveys.

The study sample included 3,660 parents of hospitalized children, 391 (10.7%) of whom had low health literacy. Of the 391 parents with low health literacy, 91 (23.3%) indicated they always needed help with reading written material from their doctor, 73 (18.7%) needed help often; and 227 (58.1%) needed help sometimes. Of the 3,269 parents with adequate health literacy, 504 (15.4%) needed help rarely and 2,765 (84.6%) indicated that they never needed help with reading written material from their doctor.

Parents with low health literacy were generally younger, lower income, used public insurance to cover their child's care, had more limited English proficiency, less education, and were more likely to be Hispanic, compared to parents with adequate health literacy (Table 1). We did not find significant differences between the adequate- and low-health literacy groups in terms of parent or child gender, child age, or medical complexity.

Length of Stay

The mean length of stay for our study population (after winsorization at the 99th percentile) was 3 days and 10 hours. Parent health literacy was a statistically significant predictor of a child's length of stay (Table 2). On average, children of parents with low health literacy stayed in the hospital 0.17 days (approximately 4 hours and 2 minutes, or 4.9% of the mean length of stay for the population) longer than children of parents with adequate health literacy (95% CI: 0.027–0.310). After adjusting for patient age, insurance type, medical complexity, and interpreter need, children of parents with low health literacy stayed in the hospital on average 0.177 days (approximately 4 hours and 15 minutes, or 5.2% of the mean length of stay for the population) longer, compared to their counterparts whose parents had adequate health literacy (95% CI: 0.015–0.340).

Unplanned Readmission

Of children in our sample, 10.5% experienced an unplanned readmission within 30 days of discharge. We did not find evidence of a significant association between parent health literacy and unplanned readmission within 30 days. Among patients whose parents had low health

literacy, 10.0% had an unplanned readmission within 30 days of discharge, compared to 10.6% of children whose parents had adequate health literacy.

Trust in Healthcare System

In bivariate analyses, low health literacy was a statistically significant predictor of parent-reported distrust of the healthcare system, though not in the direction we expected. Parents with low health literacy had lower odds of reporting distrust in the healthcare system, compared to parents with adequate health literacy (Table 3; OR = 0.67; 95% CI = 0.50–0.90). However, after adjusting for covariates the association was no longer statistically significant (OR = 0.91; 95% CI = 0.66–1.27).

Cultural Distance

Health literacy was a statistically significant predictor of parent-reported cultural distance between family and provider. In bivariate analyses, parents with low health literacy had higher odds of reporting cultural distance compared to parents with adequate health literacy (OR = 1.70; 95% CI = 1.35–2.13). This association remained significant after adjusting for confounding factors (OR = 1.38; 95% CI = 1.03–1.84).

Trust in Physician

We did not find evidence of an association between low health literacy and physician distrust in bivariate analyses (OR = 0.86; 95% CI = 0.60–1.23). Among parents with low health literacy, 27.5% had high distrust of their child's physician, compared to 30.6% of parents with adequate health literacy. After adjusting for covariates, the association between low health literacy and physician distrust remained statistically insignificant, although an association appeared possible (OR = 1.46; 95% CI = 0.92–2.33).

Partnership

In bivariate analyses, parents with low health literacy had lower odds of reporting poor partnership, compared to parents with adequate health literacy (OR = 0.34; 95% CI = 0.22–0.52). After adjusting for covariates, this association appeared less certain (OR = 0.65; 95% CI = 0.40–1.06).

The System as a Barrier

Health literacy was a statistically significant predictor of experiencing system-level barriers to care in bivariate analyses. Parents with low health literacy had higher odds of reporting the system as a barrier, compared to parents with adequate health literacy (OR = 1.48;

95% CI = 1.14–1.93). After adjusting for covariates, it appeared as though an association between low health literacy and experiencing system-level barriers was possible, though the magnitude remains uncertain (OR = 1.33; 95% CI = 0.95–1.86).

Discussion

This study evaluated the association between low parental health literacy and length of stay, unplanned readmission within 30 days, and five barriers to high-quality care among children hospitalized at a pediatric research hospital. Low parental health literacy was associated with a longer length of stay, but not with unplanned readmission. We found clear evidence that parents with low health literacy had higher odds of reporting cultural distance with their child's providers. Our analyses of poor partnership and system-level barriers to care indicated a potential association, but were less conclusive in multivariate analysis. We found no association between low health literacy and distrust of child's physician in bivariate analyses, although multivariate analyses indicated a possible association. We did not find evidence that low health literacy was associated with distrust in the healthcare system as a whole.

Parents in our sample had an overall lower prevalence of low health literacy (10.7%) compared to an estimated 28.7%[9] of parents nationwide (regardless of whether they had hospitalized children), and 27%[11] of parents in a similar study. This is likely due to several factors. As a growing urban area, the Seattle region is a wealthy and highly educated part of the country. Additionally, some parents of hospitalized children conceivably had more experience with navigating and understanding the healthcare system, compared to parents of children who had never had to be hospitalized. Participation bias may also have contributed, as parents with low literacy may have been less likely to participate in the study.

Length of Stay

Children of parents with low health literacy stayed in the hospital slightly longer (about 4 hours), on average, than children of parents with adequate health literacy. While no previous research has evaluated the association between parental health literacy and length of stay among pediatric patients, our results are consistent with a previous study conducted with hospitalized adult patients.[14] That study found that low health literacy was associated with an 11.1% longer length of stay among hospitalized general medicine patients.

The mechanism behind the association between health literacy and longer length of stay remains unclear, as health literacy and length of stay are both complex concepts. Our results could be an indication that the hospital's efforts to support families with low health literacy and other barriers translated to more time with the care team. Providers may have spent more time with parents who had low health literacy in order to ensure they understood their child's treatment plan before engaging in treatment or discharge. Alternatively, the difference in length of stay associated with health literacy may be explained by poor communication with these families and a lack of understanding among the care team of how best to support them. Given that low health literacy was associated with greater cultural distance, our results suggest that an intervention focusing on these barriers might improve quality of care for families with low health literacy. Further research into this association should take a mixed methods approach to better understand whether and how care teams delay discharge for families with low health literacy, and whether intervention is warranted.

Unplanned Readmission

Low health literacy was not associated with higher odds of unplanned readmission in our sample. This result was unexpected, as studies of adult populations have found a significant association between low health literacy and risk of hospital reutilization. A 2012 study of adult patients in an urban safety net hospital found that low health literacy was associated with a 46% higher risk of 30-day hospital reutilization.[15] Similarly, a 2013 study found that counties in Missouri with low health literacy rates had higher rates of preventable hospitalizations.[16] A likely explanation for this discrepancy is that unplanned readmission is less common among pediatric patients, who tend to be more resilient than adults. Health literacy therefore may have had less of an impact on unplanned readmission within a pediatric population.

Cultural Distance and the System as a Barrier

Our results indicate that parents with low health literacy experienced greater cultural distance with their child's providers and may have had higher odds of feeling that the healthcare system did not work well for their child in the last three months. These results were consistent with our hypotheses. Both cultural distance and system-level barriers are measures of discordance between the health system (including individual providers) and the family. Low health literacy is one of many factors – including race, culture, language, immigration status – that contribute to this discordance.

Partnership

Contrary to previous research,[11] our results suggest that parents with low health literacy reported better partnership with their child's care team, compared to parents with adequate health literacy. This discrepancy may be due to differences in study setting and population, but may also be explained by differences in how partnership was assessed. Our survey asked parents explicitly about specific behaviors their providers exhibited (e.g. encouraged me to express concerns, asked for my opinions and thoughts). In contrast, Yin et al. assessed parents' reactions to physicians' behavior, asking parents a general question of how often their child's providers helped them feel like a partner.[11]

These questions target different aspects of shared decision-making. Taken together, these results may indicate that providers' efforts to engage parents in shared decision-making may not have been effective. Our results suggest that providers were actively trying to engage with parents who have low health literacy by asking for their opinions and concerns, yet Yin et al.'s findings suggest that parents with low health literacy were less likely to feel like a partner, perhaps in spite of such efforts. Thus, traditional shared decision-making strategies (sharing information with patients, asking them about their values and preferences, and collaboratively weighing treatment options) may not be the most appropriate or effective way to engage parents with low health literacy. Further research might explore this discrepancy in more detail, as well as explore new strategies to better engage these families.

System and Physician Distrust

We did not find a significant association between parental health literacy and distrust in the healthcare system after adjusting for covariates. In fact, our unadjusted models indicated that parents with low health literacy reported greater trust in the healthcare system as a whole. Conversely, our results suggest that parents with low health literacy may have reported lower trust in their child's providers, although the association was not statistically significant in our sample.

Together, these results support the findings of a previous study of hospitalized adult cardiac patients, which used the same distrust measures. That study found that patients with lower health literacy had a higher likelihood of physician distrust, but were not more likely to distrust the healthcare system.[31] Among the many possible explanations for these findings, two seem most plausible. First, our findings support the theory outlined by Gupta, et al. that system

distrust is impacted by societal, rather than personal, factors, and that distrust of a physician is more influenced by communication barriers related to low health literacy.[31] Alternatively, our findings may have been influenced by the timing of our questions and social desirability bias. Parents were asked about trust in the healthcare system while they were in the hospital waiting to receive care for their child. They were not asked about trust in their child's physician until after the child had been discharged. Conceivably, parents may have been uncomfortable reporting high distrust in the healthcare system while surrounded by their child's care team, and more comfortable reporting distrust after they no longer felt dependent on their child's care team.

Limitations

Our study was subject to several limitations. Importantly, as we focused on a single pediatric hospital with a higher prevalence of adequate health literacy compared to the rest of the country, our results may not be generalizable to other populations. Additionally, we were potentially subject to participation bias. Parents who were unable to be at bedside during the day when the admission survey was administered, who did not speak English or Spanish, or who were uncomfortable participating were not included in the study. Finally, our study was subject to potential misclassification of health literacy among parents with limited English proficiency due to the wording of our survey, as the literacy screener we used did not distinguish between needing help reading health materials because of language rather than literacy per se. It is possible that LEP parents who are highly health literate indicated that they often needed assistance due to their limited English proficiency, rather than due to health literacy challenges.

Implications for interventions and future research

Overall, our results indicate that parental health literacy is a predictor of some aspects of patient experience in an urban pediatric hospital. The reason behind longer length of stay for low-health literacy families remains unclear and would benefit from further research. Strategies to address cultural distance, the system as a barrier, and physician distrust might be expected to improve experience of care for parents with low health literacy; whether such interventions might also increase parent involvement in shared decision-making requires further study.

However, given that the size of the association between health literacy and many of our outcomes was uncertain, health literacy is clearly not the only (and perhaps not the most important) barrier to high-quality care that families face. Many families with low health literacy also had limited English proficiency, and were more likely to be racial or ethnic minorities.

Hospitals seeking to improve quality for these patients should consider a multifaceted approach that also targets language support, cultural distance, and distrust, along with low-literacy educational materials and strategies. Approaches may also include efforts to diversify the healthcare workforce in terms of language skill, race/ethnicity and cultural background.

Hospitals might also consider administering the Single Item Literacy Screener as part of routine clinical care, as the Institute of Medicine has recommended.[4] However, unless this information is recorded in the patient's medical record and combined with interventions that better engage these patients, screening families may add additional burden and embarrassment for families, and could contribute to distrust of the healthcare system.[32]

Our study emphasizes the impact health literacy can have on multiple aspects of patient experience. Ultimately, efforts to make the health system more accessible for families with low health literacy – combined with efforts to improve families' health literacy – would empower patients to engage in their own care decisions and move our healthcare system closer to achieving the Triple Aim.

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Tables and Figures

Table 1: Demographic and clinical characteristics of children hospitalized at a large, freestanding pediatric hospital from October 2014-December 2015, stratified by parent health literacy.

Measure	Low parent health literacy N = 391		Adequate parent health literacy N = 3,269	
Family total income, N (%)				
<$15,000	72	(19.3)	220	(6.8)
$15,000-$29,999	103	(27.5)	368	(11.4)
$30,000 - $49,999	44	(11.8)	364	(11.2)
≥$50,000	40	(10.7)	1,622	(50.1)
Declined	115	(30.8)	663	(20.5)
Insurance type, N (%)				
Commercial	68	(17.4)	1,900	(58.1)
Public/Other	323	(82.6)	1,363	(41.7)
Missing	--	--	6	(0.2)
Parent age, N (%)				
18-24	36	(9.2)	184	(5.6)
25-34	140	(35.8)	1,077	(33.0)
35-44	149	(38.1)	1,322	(40.4)
45-54	54	(13.8)	575	(17.6)
55-64	5	(1.3)	71	(2.2)
65-74	1	(0.3)	8	(0.2)
75 or older	1	(0.3)	--	--
Missing	5	(1.3)	32	(1.0)
Parent male gender, N (%)	76	(19.4)	692	(21.2)
Parent interpreter need*, N (%)				
Yes	204	(52.2)	86	(2.6)
No	184	(47.1)	3,168	(96.9)
Missing	3	(0.8)	15	(0.5)
Parent's highest education, N (%)				
High school or less	274	(70.1)	660	(20.2)
Some college	63	(16.1)	1,211	(37.0)
Bachelor's degree or more	46	(11.8)	1,374	(42.0)
Missing	8	(2.1)	24	(0.8)
Child male gender, N (%)	207	(52.9)	1,701	(52.0)
Child's race/ethnicity, N (%)				
Non-Hispanic White	69	(17.7)	1,860	(57.0)
Black	18	(4.6)	149	(4.6)
Hispanic	243	(62.2)	466	(14.3)
Asian	15	(3.8)	203	(6.2)
Other/Mixed	46	(11.8)	585	(17.9)
Missing	--	--	6	(0.2)

Child's age (years), N (%)				
<2	91	(23.3)	769	(23.5)
2-5	68	(17.4)	586	(17.9)
5-13	141	(36.1)	1,180	(36.1)
13-18	90	(23.0)	721	(22.1)
>18	1	(0.3)	13	(0.4)
Child's medical complexity, N (%)				
Non-chronic	125	(32.0)	1,119	(34.2)
Non-complex chronic	107	(27.4)	946	(28.9)
Complex chronic	159	(40.7)	1,203	(36.8)
Missing	--	--	1	(<0.1)
Length of stay (days),** mean (SD)	3.37	(4.59)	2.84	(3.61)
Unplanned readmission within 30 days, N (%)	39	(9.97)	345	(10.55)

**based on self-reported English proficiency and preferred language for care*[28]
***winsorized at the 99th percentile*

Table 2: Associations between parent low health literacy and child clinical outcomes.

Outcome	Unadjusted Coefficient	95% CI	P-value	Adjusted Coefficient**	95% CI	P-value
Length of stay (days)	0.17*	0.03–0.31	0.02	0.18*	0.02–0.34	0.03
	Unadjusted OR	**95% CI**	**P-value**	**Adjusted OR****	**95% CI**	**P-value**
Unplanned readmission within 30 days	0.94	0.66–1.34	0.72	0.95	0.61–1.49	0.83

** statistically significant association*
***adjusted for patient age, insurance type, medical complexity, and parent interpreter need*

Table 3: Associations between parent low health literacy and odds of parent-reported barriers to high-quality care.

Outcome	Unadjusted OR	95% CI	P-value	Adjusted OR**	95% CI	P-value
Distrust in system	0.67*	0.50–0.90	0.01	0.91	0.66–1.27	0.59
Cultural distance	1.70*	1.35–2.13	<.001	1.38*	1.03–1.84	0.03
Distrust in child's physician	0.86	0.60–1.23	0.41	1.46	0.92–2.33	0.11
Poor Partnership	0.34*	0.22–0.52	<.001	0.65	0.40–1.06	0.08
System as a barrier	1.48*	1.14–1.93	<.01	1.33	.95–1.86	0.10

** statistically significant association*

***Adjustment variables:*

Trust in system: patient insurance type, race/ethnicity, medical complexity, and parent interpreter need.
Cultural distance: patient insurance type, race/ethnicity, and parent interpreter need.
Trust in physician: patient insurance type, race/ethnicity, medical complexity, and parent interpreter need.
Partnership: patient insurance type, medical complexity, and parent interpreter need.
System as a barrier: patient insurance type, medical complexity, and parent interpreter need.

Appendix I: Survey Measures

Measure	Survey Questions	Response Scores
Admission Survey (within 72 hours of admission)		
Distrust in system *Summed responses for final score between 5 and 25; higher value indicates greater distrust.*	1. The health care system covers up its mistakes.	Strongly agree: 5 Agree: 4 Neutral: 3 Disagree: 2 Strongly disagree: 1
	2. The health care system puts making money above patients' needs.	Strongly agree: 5 Agree: 4 Neutral: 3 Disagree: 2 Strongly disagree: 1
	3. Patients get the same medical treatment from the health care system, no matter what the patient's race or ethnicity.	Strongly agree: 1 Agree: 2 Neutral: 3 Disagree: 4 Strongly disagree: 5
	4. The health care system lies to make money.	Strongly agree: 5 Agree: 4 Neutral: 3 Disagree: 2 Strongly disagree: 1
	5. The health care system experiments on patients without them knowing.	Strongly agree: 5 Agree: 4 Neutral: 3 Disagree: 2 Strongly disagree: 1
Cultural distance *Averaged responses for final score between 1 and 6; higher value indicates greater cultural distance.*[12]	For the following questions, please think about the main doctor(s) caring for your child during this hospital stay so far. 1. The way my child's doctor(s) and I speak is…	Very similar: 1 Moderately similar: 2 Slightly similar: 3 Slightly different: 4 Moderately different: 5 Very different: 6
	2. The way my child's doctor(s) and I reason about problems is…	Very similar: 1 Moderately similar: 2 Slightly similar: 3 Slightly different: 4 Moderately different: 5 Very different: 6
	3. My child' doctor(s) and I have ____ styles of communication.	Very similar: 1 Moderately similar: 2 Slightly similar: 3

		Slightly different: 4 Moderately different: 5 Very different: 6
	4. My child's doctor(s) and I have ____ general values in life.	Very similar: 1 Moderately similar: 2 Slightly similar: 3 Slightly different: 4 Moderately different: 5 Very different: 6
System as a barrier *Final score between 0 and 100; higher value indicates greater perceived barriers.*	In the last 3 months (or since birth, if your child is less than 3 months old), how often did the health care system work well for your child?	Never: 100 Almost Never: 75 Sometimes: 50 Often: 25 Almost Always: 0
Discharge Survey (within 2 weeks of discharge)		
Distrust in child's physician *Summed responses for final score between 10 and 50; higher value indicates greater distrust.*	1. My child's doctors will do whatever it takes to get my child all the care he or she needs.	Strongly agree: 1 Agree: 2 Neutral: 3 Disagree: 4 Strongly disagree: 5
	2. Sometimes my child's doctors care more about what is convenient for him or her than about my child's medical needs.	Strongly agree: 5 Agree: 4 Neutral: 3 Disagree: 2 Strongly disagree: 1
	3. My child's doctors' medical skills are not as good as they should be.	Strongly agree: 5 Agree: 4 Neutral: 3 Disagree: 2 Strongly disagree: 1
	4. My child's doctors are extremely thorough and careful.	Strongly agree: 1 Agree: 2 Neutral: 3 Disagree: 4 Strongly disagree: 5
	5. I completely trust my child's doctors' decisions about which medical treatments are best for my child.	Strongly agree: 1 Agree: 2 Neutral: 3 Disagree: 4 Strongly disagree: 5

	6. My child's doctors are totally honest in telling me about all of the different treatment options available for my child's condition.	Strongly agree: 1 Agree: 2 Neutral: 3 Disagree: 4 Strongly disagree: 5
	7. My child's doctors only think about what is best for my child.	Strongly agree: 1 Agree: 2 Neutral: 3 Disagree: 4 Strongly disagree: 5
	8. Sometimes my child's doctors do not pay full attention to what I am trying to tell him or her.	Strongly agree: 5 Agree: 4 Neutral: 3 Disagree: 2 Strongly disagree: 1
	9. I have no worries about putting my child's life in his or her doctors' hands.	Strongly agree: 1 Agree: 2 Neutral: 3 Disagree: 4 Strongly disagree: 5
	10. All in all, I have complete trust in my child's doctors.	Strongly agree: 1 Agree: 2 Neutral: 3 Disagree: 4 Strongly disagree: 5
Poor partnership *Summed responses for final score between 3 and 18; higher value indicates worse partnership.*	1. The doctor(s) encouraged me to express my concerns and worries.	Strongly agree: 1 Moderately agree: 2 Slightly agree: 3 Slightly disagree: 4 Moderately disagree: 5 Strongly disagree: 6
	2. The doctor(s) asked for my opinion on what to do about my child's medical condition.	Strongly agree: 1 Moderately agree: 2 Slightly agree: 3 Slightly disagree: 4 Moderately disagree: 5 Strongly disagree: 6
	3. The doctor(s) asked for my thoughts about my child's health.	Strongly agree: 1 Moderately agree: 2 Slightly agree: 3 Slightly disagree: 4 Moderately disagree: 5 Strongly disagree: 6