RESEARCH ARTICLE

Identifying Modifiable Health Care Barriers to Improve Health Equity for Hospitalized Children

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ABSTRACT

BACKGROUND: Children from socially disadvantaged families experience worse hospital outcomes compared with other children. We sought to identify modifiable barriers to care to target for intervention.

METHODS: We conducted a prospective cohort study of hospitalized children over 15 months. Caregivers completed a survey within 3 days of admission and 2 to 8 weeks after discharge to assess 10 reported barriers to care related to their interactions within the health care system (eg, not feeling like they have sufficient skills to navigate the system and experiencing marginalization). Associations between barriers and outcomes (30-day readmissions and length of stay) were assessed by using multivariable regression. Barriers associated with worse outcomes were then tested for associations with a cumulative social disadvantage score based on 5 family sociodemographic characteristics (eg, low income).

RESULTS: Of eligible families, 61% (n = 3651) completed the admission survey; of those, 48% (n = 1734) completed follow-up. Nine of 10 barriers were associated with at least 1 worse hospital outcome. Of those, 4 were also positively associated with cumulative social disadvantage: perceiving the system as a barrier (adjusted β = 1.66; 95% confidence interval [CI] 1.02 to 2.30), skill barriers (β = 3.82; 95% CI 3.22 to 4.43), cultural distance (β = 1.75; 95% CI 1.36 to 2.15), and marginalization (β = .71; 95% CI 0.30 to 1.11). Low income had the most consistently strong association with reported barriers.

CONCLUSIONS: System barriers, skill barriers, cultural distance, and marginalization were significantly associated with both worse hospital outcomes and social disadvantage, suggesting these are promising targets for intervention to decrease disparities for hospitalized children.

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Children from families with low income, of minority race and/or ethnicity, and with limited English proficiency (LEP) are at increased risk for worse outcomes after hospitalization, with longer length of stay (LOS), greater risk of readmission, and worse health-related quality of life (HRQL) compared with other children.[1–11] However, the mechanisms by which these disparities occur are incompletely understood. Many factors likely contribute, occurring both within and outside the health care system and before and after hospital arrival. These include barriers to access and delayed presentation due to financial concerns, competing priorities, and/or previous negative experiences[12–16]; less family-centered communication, lower trust, and less partnership between families and providers[17–20]; increased rates of adverse events[21–23]; and provider bias.[24,25]

All of these factors must be addressed to achieve equity, but the tools, expertise, and time required for each will vary. For example, although efforts to address bias are essential, provider behavior is slow to change.[26] It is therefore appealing to identify potentially modifiable attributes that occur within the health care setting to address in the near term. For example, disparate outcomes due to difficulty in navigating the health care system could be addressed through enhanced care coordination or patient navigation.

Thus, our objective was to identify potentially modifiable health care barriers experienced by families of hospitalized children to isolate promising targets for future intervention. We approached this in 3 phases: (1) identifying barriers to care associated with worse hospital outcomes, (2) identifying which of those barriers were also associated with greater social disadvantage, and (3) identifying the relative contribution of individual social disadvantage factors to the association with barriers to care.

METHODS

Study Population

We prospectively studied a cohort of children admitted to a freestanding, quaternary-care children's hospital between October 1, 2014, and December 31, 2015. The electronic medical record was used to screen children for eligibility. Children and caregivers were eligible if they were admitted to a medical or surgical unit, had not previously participated during the past 2 months, were not in strict reverse isolation secondary to immunocompromise, were not admitted for suspected child abuse, and spoke English or Spanish. Other languages were excluded because of a lack of validated survey measures. We excluded children admitted for scheduled chemotherapy or to the psychiatry, rehabilitation, or bone marrow transplant units because hospital outcomes such as LOS and HRQL are distinct for these patients and could significantly skew results. Eligible caregivers were approached and enrolled by research assistants within 72 hours of admission and asked to complete both an admission survey at enrollment and a follow-up survey 2 to 8 weeks postdischarge. Caregivers could self-administer the Web-based surveys or complete them via telephone with a bilingual research assistant.

Survey Administration

Both surveys are routinely administered to evaluate changes in HRQL resulting from hospitalization; we added previously validated measures to these ongoing surveys for this study. Most measures were caregiver reported, although children ≥8 years old were also invited to complete HRQL measures. Caregivers who completed the admission survey were e-mailed the follow-up survey link or called, depending on preference, 2 to 4 weeks after discharge. Seventy-two percent of completions occurred between 2 and 6 weeks after discharge. Caregivers of patients readmitted within 30 days were ineligible for the follow-up survey.

Survey Measures

Survey measures included sociodemographic disadvantage markers (eg, low income), caregiver experiences, abilities and attitudes that may affect health care system navigation (hereafter referred to as "barriers to care"), and HRQL during and after hospitalization. The previously validated barriers-to-care measures (Table 1) were chosen because each relates to the interaction between the caregiver and the health care system, has a known relationship with health or health care outcomes, has a potential relationship with sociodemographic characteristics, and could be modifiable with the right intervention (as opposed to measures such as race and/or ethnicity). Barriers-to-care measures were scored so that higher scores reflected greater barriers.

For HRQL, changes in physical functioning after hospital discharge were assessed by using the Pediatric Quality of Life Inventory 4.0 Generic Core or Infant Scales (PedsQL) physical functioning subscale.[27,28] We used the physical functioning subscale because hospital care most strongly influences a child's physical (rather than psychosocial) functioning.[29,30] For analyses, caregiver-proxy report was used for patients <13 years old. For teenagers, self-report was used when available; otherwise, caregiver-proxy report was used.

Additional Data

Hospital administrative records were used to collect data on child age, sex, insurance type, caregiver-reported child race and/or ethnicity, preferred language for medical care, medical complexity, LOS (measured to the one-tenth of a day), and unplanned 30-day readmissions. Medical complexity was determined by using the Pediatric Medical Complexity Algorithm, which classifies children as having no chronic conditions, noncomplex chronic conditions, or complex chronic conditions.[31] Inpatient readmissions were classified as unplanned by using the methods developed by Berry et al[32] (Table 1).

The hospital's institutional review board approved this study.

Analytic Approach

Analysis occurred in 3 phases: First, we identified caregiver-reported barriers to care associated with hospital outcomes (Fig 1). To identify potential targets for intervention to improve outcomes for children with social risk, in phase 2, we identified those barriers associated with both worse outcomes and a cumulative social disadvantage score. To better tailor future interventions, in phase 3, for those barriers identified as potential targets in

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TABLE 1 Description of Data Elements Used in the Study, Including Social Disadvantage Factors, Caregiver-Reported Barriers-To-Care Measures, and Hospital Outcomes

Measure	Construct and Description	Data Source
Social disadvantage factors		
US census question followed by preferred language for care[60]	Interpreter need: 2-item, sequential approach with excellent sensitivity and specificity for identifying individuals who are likely to benefit from interpretation during medical care	Hospital administrative data and admission survey
Caregiver report of highest educational attainment	Low education: defined as caregiver with a high school degree or less	Admission survey
Caregiver report of annual family income	Low income: annual household income <$30 000	Admission survey
Primary payer for current hospital stay	Public insurance: Medicaid and Medicare; no insurance and charity care were also classified with public insurance	Hospital administrative data
US census questions regarding race and ethnicity	Minority race and/or ethnicity: caregiver report of child's race and/or ethnicity as anything other than non-Hispanic white	Hospital administrative data
Barriers-to-care measures		
Barriers to Care Questionnaire: System[48]	System as a barrier: 1 item measuring the caregiver's perception of how well the health care system has worked for their child in the past 3 mo (score range 0–100)	Admission survey
Barriers to Care Questionnaire: Skills[48]	Skills barriers: 8 items measuring the perceived mismatch between the caregiver's skills and what the health care system requires of them; items include the degree to which caregivers have enough information about how the system works, the degree to which they understand doctor's orders, their ability to get referrals to specialists, and their ability to get enough help with paperwork (score range 0–100)	Admission survey
Cultural Distance Scale[47]	Cultural distance: 4 items measuring how similar or different the caregiver feels they are compared with the child's doctors, with questions about how they speak, how they reason about problems, communication styles, and general values in life (score range 0–100)	Admission survey
Barriers to Care Questionnaire: Marginalization[48]	Marginalization barriers: 11 items measuring feelings of marginalization and disrespect within the health care system; items include not being listened to, impatient or intimidating doctors, not being treated with respect, and being judged on your appearance, ancestry, or accent (score range 0–100)	Admission survey
Health Care System Distrust scale[61]	System distrust: 5 items measuring trust in the health care system; items capture the degree to which the caregiver agrees, for example, that the system lies to make money, covers up its mistakes, and discriminates on the basis of race and ethnicity (score range 5–25)	Admission survey
Barriers to Care Questionnaire: Expectations[48]	Expectation barriers: 7 items measuring ways in which the health care system might fail to meet expectations for acceptable care; items include lack of coordination between the child's doctors and other parts of the health care system, medical errors, and doctors treating symptoms without finding the cause of an illness (score range 0–100)	Admission survey
Barriers to Care Questionnaire: Knowledge and Beliefs[48]	Knowledge barriers: 4 items measuring perceived discordance between the caregiver's and providers' beliefs and recommendations for	Admission survey

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TABLE 1 Continued

Measure	Construct and Description	Data Source
	treatment and health; items include disagreeing with doctors' orders and doctors and nurses having different ideas about health than the caregiver does (score range 0–100)	
Perceived Efficacy in Patient-Physician Interactions[62,63]	Health care self-efficacy: 10-item tool measuring the caregiver's confidence in interacting with health care professionals and organizations; items include confidence in knowing what questions to ask, getting a doctor to do something about their main health concern for their child, and understanding what the doctor said (score range 10–50)	Admission survey
Wake Forest Physician Trust Scale[64]	Distrust of providers: 10-item tool measuring trust in the specific physician(s) providing care to the child; items include the degree to which the caregiver believes that the doctors only care about what is best for the child, that the doctors are thorough and careful, and that they will do whatever it takes to get the child needed care (score range 10–50)	Follow-up survey
Partnership-building subscale of Parents' Perceptions of Physicians' Communicative Behavior[65]	Lack of partnership: 3 items assessing provider-caregiver partnership; items include the degree to which the doctor encouraged the caregiver to express worries and concerns and the degree to which they asked for the caregiver's opinions on what to do for the child's medical condition (score 3–18)	Follow-up survey
Hospital outcomes		
PedsQL Generic Core or Infant Scales[27,66]	HRQL: 23–45 items (depending on child age) assessing physical and psychosocial functioning collected at admission and follow-up. The change score is calculated as the difference between the follow-up and admission survey scores (each scaled 0–100). For analyses, caregiver report was used for patients <13 y old. For teenagers, self-report was used when available; otherwise, caregiver report was used.	Admission and follow-up surveys
Hospital LOS	Measured as a continuous variable to the one-tenth of a day	Hospital administrative data
Unplanned 30-d readmissions[32]	30-d unplanned readmissions: readmissions to inpatient or observation status within 30 d of discharge after excluding readmissions with procedure codes that are likely to be related to a planned procedure	Hospital administrative data

phase 2, we identified the relative contribution of each social disadvantage factor included in the social disadvantage score.

Phase 1: Identifying Barriers to Care Associated With Hospital Outcomes

For phase 1, the 10 survey-based barriers-to-care scores were the main predictors. Outcomes were modeled on the basis of 10-unit differences in the barriers-to-care scores.

Hospital outcomes were HRQL change scores, LOS, and unplanned 30-day readmissions. LOS was winsorized such that the 99th percentile was assigned to the most extreme values to prevent skewing of the results.

We modeled HRQL change scores as a continuous outcome using linear regression and unplanned readmissions as a dichotomous outcome using logistic regression. LOS was modeled by using a generalized linear model with a log-link and γ distribution. Models accounted for clustering on patient and controlled for patient age and medical complexity.

Phase 2: Identifying Barriers to Care Associated With Social Disadvantage Score

The social disadvantage score was the main predictor in this analysis. To create this score, 1 point was assigned for each of the following: public or no insurance, minority race and/or ethnicity, low income, low education, and interpreter need (score range 0–5; Table 1). We chose this approach on the basis of previous studies demonstrating clear evidence for an additive rather than threshold relationship

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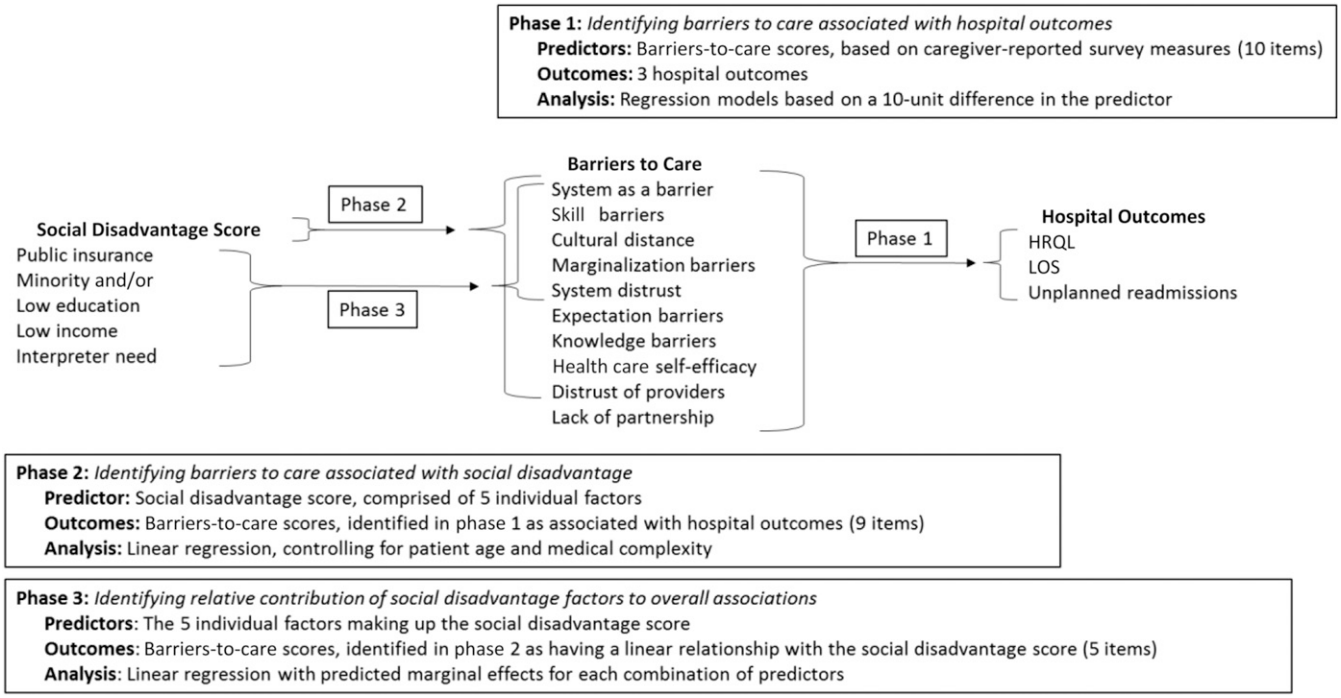

FIGURE 1 Schematic of the 3 phases of the analytic approach.

for a variety of risks and outcomes in children to reflect the way in which risk factors tend to aggregate together to produce a disproportionate impact on a subset of individuals.[33–38] Approximately 24% of participants declined to report income or did not know; therefore, we used multiple imputation, with 20 rounds of imputation, for missing income information before calculating the risk score.[39,40]

Nine of the 10 barriers-to-care scores (Table 1) that were identified in phase 1 as being significantly associated with ≥1 worse hospital outcome served as the outcomes for these analyses; the majority were associated with LOS.

We modeled each barriers-to-care score using linear regression, with robust SEs accounting for clustering on patient and controlling for patient age and medical complexity. We imputed missing income data using multiple imputation with chained equations. We conducted analyses on each multiply imputed data set and pooled the results to generate final results.[41] We modeled the social disadvantage score as a continuous variable to assess for a linear trend in its relationship to each of the 9 barriers-to-care scores.

Phase 3: Identifying the Relative Contribution of Social Disadvantage Factors to Overall Associations

All possible combinations of the 5 individual factors constituting the social disadvantage score served as the main predictors.

We used the 5 barriers-to-care scores demonstrating positive linear relationships with the social disadvantage score in phase 2 as the outcomes in these analyses.

To identify the relative contribution of each social disadvantage factor, we fitted a linear regression model for all barriers-to-care scores, including all social disadvantage factors, as dichotomous predictors. We controlled for age and medical complexity, used robust SEs accounting for clustering within patient, and addressed missing data with multiple imputation. We then assessed the predicted marginal effects on that barriers-to-care score from each combination of social disadvantage factors. In this way, we used our models to predict how much of a problem a caregiver would report each barrier to care to be for every combination of individual social risk factors.

RESULTS

During the 15-month study, there were 5992 families eligible for the admission survey. Of those, 1083 (18.1%) declined, 503 (8.4%) had no parent or guardian available, 455 (7.6%) were unable to be approached within 72 hours, 300 (5.0%) completed the main survey but did not complete measures for this study, and 3651 (60.9%) completed at least 1 of the barriers-to-care measures. Of those who completed the admission survey, 1734 (47.5%) also completed the follow-up survey. Less than 3% of admission surveys (84 of 3651) and <2% of follow-up surveys (19 of 1734) were completed by caregivers who were repeat study participants.

Of survey participants, almost half were publicly insured and approximately half were non-Hispanic white; ~10% were likely to need interpretation (Table 2). Approximately 40% had a bachelor's degree

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or more, and >40% reported an annual household income >$50 000. Before imputation, 35% of respondents had no social disadvantage factors, 28% had 1, 14% had 2, 11% had 3, 8% had 4, and 4% had 5.

Phase 1: Caregiver-Reported Barriers to Care Associated With Hospital Outcomes

Nine of 10 barriers-to-care scores were significantly associated with at least 1 hospital outcome (Table 3). Skill barriers and distrust of providers were significantly associated with less improvement in HRQL, although these differences were below the minimal clinically important difference of 4.5 (scale 0–100).[27] Three barriers-to-care scores were associated with increased odds of unplanned readmission: the system as a barrier (odds ratio [OR] 1.05; 95% confidence interval [CI] 1.01 to 1.10), expectation barriers (OR 1.08; 95% CI 1.02 to 1.15), and knowledge barriers (OR 1.07; 95% CI 1.10 to 1.14). Eight barriers-to-care scores were associated with increased LOS, with increases ranging from 3% to 12% for each 10-point increase in the reported barrier; this amounts to an additional 2 to 9 inpatient hours beyond a typical LOS. Lack of partnership was not associated with any hospital outcomes.

Phase 2: Identifying Barriers to Care Associated With Social Disadvantage

Of the 9 barriers-to-care scores associated with worse hospital outcomes, 5 were significantly associated with cumulative social disadvantage (Table 4). Four of these had a positive relationship, indicating that greater social disadvantage was associated with greater barriers to care. These included the system as a barrier (adjusted β 1.66; 95% CI 1.02 to 2.30), skill barriers (β 3.82; 95% CI 3.22 to 4.43), cultural distance (β 1.75; 95% CI 1.36 to 2.15), and marginalization barriers (β .71; 95% CI 0.30 to 1.11). One barrier to care, system distrust, had an inverse relationship with social disadvantage, meaning that greater social disadvantage was associated with less distrust of the health care system (β −.33; 95% CI −0.43 to −0.23).

Phase 3: Identifying the Relative Contribution of Social Disadvantage Factors to Overall Associations

Across all 5 barriers to care included in phase 3, the various social disadvantage factors we considered clearly had a cumulative effect on the degree of barrier reported, with low income being associated with the most pronounced increases in barriers, as seen in Supplemental Fig 2. Interpreter need, in contrast, was associated with more modest increases or decreases in reported barriers depending on which barrier was being considered. For example, both alone and combined with other factors, interpreter need was associated with increased skill barriers and cultural distance but decreased marginalization barriers and system distrust.

DISCUSSION

In this study of 3651 caregivers of hospitalized children, we found that caregiver-reported barriers to care related to the system, skills, cultural distance, and marginalization were associated with worse hospital outcomes, namely longer LOS and/or increased 30-day readmissions. These barriers were more likely to occur among families with greater social disadvantage. We also found that low income was the strongest predictor of reporting greater barriers to care across categories; interpreter need was associated with less markedly increased, or in some cases decreased, reported barriers to care.

This study adds to existing literature on barriers to care for disadvantaged children by exploring which barriers may contribute to disparate outcomes in the hospital setting. Previous studies have documented the wide range of health care barriers faced by children from low-income, minority, and LEP families, including worse access to primary and specialty care,[16,42,43] lower family centeredness and worse communication once in the health care system,[19,20] worse comprehension of diagnoses and instructions,[44–46] and lower trust in providers.[18,47] Each could plausibly contribute to the worse outcomes observed across studies for low-income and minority children.[1–10] Our results highlighted 4 specific caregiver-reported barriers as promising for intervention: the system as a barrier, skill barriers, marginalization barriers, and cultural distance.

The system as a barrier was a single, global item reflecting how responsive the health care system has been to the child's needs.[48] We found that caregivers who reported the system as a barrier had children with increased LOS and higher odds of unplanned readmission. This single item could help identify those who would benefit from additional support. Potential interventions include patient navigation,[49,50] enhanced care coordination,[51–53] or connecting patients to primary care medical homes.[54]

Skill barriers measured the caregiver's assessment of their own skills for navigating the health care system and included items related to communication, comprehension, and having enough health care knowledge.[48] Skill barriers are associated with caregiver-reported quality of primary care and child HRQL.[48] In our study, caregivers reporting skill barriers had children with increased LOS, and these barriers were strongly associated with social disadvantage. Although caregiver skills are not readily modifiable, interventions to decrease the skills required of caregivers would render their current skills adequate for navigating the system. Interventions could include patient navigation, low-literacy educational materials, improved interpreter use, and simplified, streamlined referral processes, among others.

Cultural distance reflected the degree of similarity or difference that caregivers perceived between themselves and their children's providers.[47,55] It framed culture in terms of shared values, communication, and reasoning rather than asking about shared heritage. Cultural distance is associated with trust, quality of care, satisfaction, and intention to adhere along with degree of reported pain in controlled laboratory studies, suggesting a powerful role in influencing experience.[47,56,57] We found that caregivers reporting greater cultural distance had children with increased LOS,

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TABLE 2 Characteristics of Patients and Caregivers Who Completed Admission Survey Questions and Follow-up Surveys

	Admission Survey (N = 3651)	Admission and Follow-up Surveys (N = 1734)
Insurance type, *n* (%)		
Commercial	1971 (54.1)	948 (54.7)
Public	1674 (45.9)	786 (45.3)
Male sex, *n* (%)	1899 (52.1)	885 (51.0)
Race and/or ethnicity, *n* (%)		
Non-Hispanic white	1922 (52.7)	935 (53.9)
African American or Black	156 (4.3)	54 (3.1)
Hispanic	711 (19.5)	360 (20.8)
Asian American	220 (6.0)	100 (5.8)
Other, multiracial, or unknown	636 (17.5)	285 (16.4)
Language for care, *n* (%)		
English	3321 (91.1)	1538 (88.7)
Spanish	301 (8.3)	184 (10.6)
Other	23 (0.6)	12 (0.7)
Likely to need interpretation, *n* (%)[a]	280 (7.9)	165 (10.1)
PMCA		
Nonchronic	1227 (33.6)	567 (32.7)
Noncomplex chronic	1042 (28.6)	480 (27.7)
Complex chronic	1381 (37.8)	687 (39.6)
Income, $		
<15 000	282 (7.7)	111 (6.4)
15 000–29 000	462 (12.7)	220 (12.7)
30 000–50 000	402 (11.0)	187 (10.8)
>50 000	1627 (44.5)	789 (45.5)
Declined or missing	878 (24.0)	427 (24.6)
Parent highest education, *n* (%)		
Less than high school	333 (9.2)	180 (10.5)
High school graduate	599 (16.6)	277 (16.1)
Some college	1262 (34.9)	544 (31.7)
Bachelor's degree or more	1425 (39.4)	716 (41.7)
Patient age, y, mean (SD)	6.9 (5.5)	6.9 (5.5)
LOS, d, mean (SD)	3.1 (5.6)	3.1 (4.4)
PedsQL change score, mean (SD)[b]		
Total	—	22.0 (24.1)
Physical	—	28.9 (33.6)
Psychosocial	—	15.1 (21.7)
30-d unplanned readmission, *n* (%)	387 (10.6)	126 (7.3)
Cumulative social disadvantage score[c]		
0	958 (34.8)	478 (37.0)
1	768 (27.9)	360 (27.8)
2	395 (14.4)	160 (12.4)
3	295 (10.7)	129 (10.0)
4	225 (8.2)	99 (7.7)
5	110 (4)	67 (5.2)

PMCA, Pediatric Medical Complexity Algorithm; —, not applicable.

[a] This combines self-reported degree of English proficiency with preferred language for communicating on the basis of survey responses (Table 1).

[b] Only shown for follow-up because the calculation of the change score requires admission and follow-up results.

[c] Shown only for those with complete data (before multiple imputation): N = 2751 for the admission survey and N = 1293 for the follow-up survey.

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TABLE 3 Adjusted Associations Between 10-Unit Change in Caregiver-Reported Barriers and Hospital Outcomes

Barrier to Care	Hospital Outcomes								
	HRQL[a]			LOS[b]			Readmission[c]		
	n	β Coefficient	95% CI	*n*	GLM Coefficient	95% CI	*n*	OR	95% CI
System barrier	1304	−.34	−1.02 to 0.35	3390	1.03[d]	1.02 to 1.05	3390	1.05[d]	1.01 to 1.10
Skill barrier	1257	−1.74[d]	−2.67 to −0.81	3273	1.04[d]	1.02 to 1.06	3273	1.01	0.96 to 1.06
Cultural distance	1318	−1.85	−2.05 to 0.35	3395	1.04[d]	1.01 to 1.06	3395	1.01	0.94 to 1.08
Marginalization barriers	1259	−.18	−1.27 to 0.91	3225	1.06[d]	1.04 to 1.09	3225	1.03	0.96 to 1.10
System distrust	1280	−.06	−0.97 to 0.84	3292	1.11[d]	1.01 to 1.22	3292	1.34	0.98 to 1.82
Expectation barriers	1267	.30	−0.69 to 1.30	3276	1.07[d]	1.05 to 1.10	3276	1.08[d]	1.02 to 1.15
Knowledge barriers	1300	.46	−0.60 to 1.51	3362	1.07[d]	1.04 to 1.09	3362	1.07[d]	1.01 to 1.14
Health care self-efficacy	1247	.62	−0.88 to 2.12	3216	1.12[d]	1.04 to 1.20	3216	1.11	0.88 to 1.39
Distrust of providers	1245	−1.64[d]	−2.97 to −0.32	1685	1.01	0.92 to 1.11	1685	1.12	0.81 to 1.54
Lack of partnership	1262	−.65	−1.74 to 0.45	1713	0.99	0.80 to 1.21	1713	1.14	0.53 to 2.45

Adjusted for age and medical complexity and clustered on patient. GLM, generalized linear model.

[a] HRQL physical functioning change score (range 0–100) modeled by using linear regression. Caregiver-proxy report was used for patients <13 y old. For patients ≥13 y old, self-report was used when available; otherwise, caregiver-proxy report was used.

[b] LOS winsorized at the 99th percentile and modeled by using a GLM with log-link and γ distribution.

[c] OR for 30-d unplanned readmission modeled by using logistic regression.

[d] Statistically significant result: $P < .05$.

and degree of cultural distance was strongly associated with social disadvantage. Interventions to bridge cultural distance could include hiring providers and staff to reflect the patient populations, cultural humility and communication training, and culturally concordant patient navigators or patient advocates.

Marginalization barriers reflected caregivers feeling disrespected or otherwise marginalized within the health care system.[48] Among children with asthma, marginalization barriers are associated with fewer primary care or subspecialty visits, worse quality of primary care, and worse HRQL.[48,58] We found that caregivers reporting marginalization barriers had children with increased LOS. Potential interventions addressing marginalization barriers include equity, diversity, and inclusion training for providers and staff; hiring to promote a diverse workforce; redesigning hospital spaces to make them welcoming and easy to navigate; and patient advocates to help caregivers speak up when they have not been treated with respect.

Low income was the strongest predictor of greater reported barriers to care, alone and across combinations, for each barrier we examined. Tailoring interventions to these families would be expected to lead to greater improvements in experienced barriers and child hospital outcomes.

TABLE 4 Adjusted Association Between Social Disadvantage Scores and Caregiver-Reported Barriers to Care

Barriers to Care	*n*	Social Disadvantage Score, β	95% CI	*P*
System barrier	3219	1.66	1.02 to 2.30	<.001
Skill barriers	3143	3.82	3.22 to 4.43	<.001
Cultural distance	3221	1.75	1.36 to 2.15	<.001
Marginalization barriers	3103	.71	0.30 to 1.11	.001
System distrust	3137	−.33	−0.43 to −0.23	<.001
Expectation barriers	3121	.02	−0.43 to 0.47	.91
Knowledge barriers	3196	.23	−0.16 to 0.63	.24
Health care self-efficacy	3052	−.12	−0.25 to 0.01	.06
Distrust of providers	1489	−.15	−0.3 3 to 0.02	.09

Adjusted for medical complexity and child age and clustered on patient.

Interpreter need had the weakest association with reported barriers to care; in some cases, it predicted modest increases, and in other cases, it predicted decreased barriers. Although this may reflect the high-quality interpreter services at the study hospital, it more likely reflects differential survey-response patterns[59] and perhaps low expectations. Because most LEP caregivers are immigrants with previous experience of another health care system, they may have lower expectations of the US system and therefore report fewer subjective difficulties. This may also help explain the otherwise surprising finding that greater social disadvantage was associated with lower system distrust in our population, primarily driven by those with interpreter need. This is important to remember when planning intervention evaluations because it may not always be helpful to compare reported barriers between LEP and English-proficient populations.

This study has several limitations. It was conducted at a single, quaternary-care institution, so results may not be generalizable. Participation in hospital-wide survey studies tends to select less

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disadvantaged families, so these results likely do not reflect the full range of disadvantaged families within our institution, and we were unable to compare respondents to nonrespondents because of institutional review board limitations.[29] We allowed repeat participation, which although infrequent could have influenced our results. In addition, the enrollment survey was administered while caregivers were physically in the hospital, which could have led to positive response bias. The social disadvantage score, although useful for capturing the cumulative effects of social disadvantage, is deficit based and does not capture caregiver and family strengths that may mitigate those effects. Finally, we had missing income data for nearly one-quarter of our survey respondents. We used multiple imputation to retain those families in the analysis and account for the resulting uncertainty in our estimates, but additional uncertainty may remain.

CONCLUSIONS

In this study, we identified 4 potentially modifiable barriers to care as promising targets for intervention: the system as a barrier, skill barriers, cultural distance, and marginalization barriers. These barriers were associated with both greater social disadvantage and worse hospital outcomes. Low income had the strongest association with reported barriers to care, whereas interpreter need had the weakest, which is consistent with previously described survey-response patterns. Interventions to help the health care system better meet patients and families where they are by bridging cultural differences, decreasing the skills required of families, creating a more inclusive environment, and assisting with system navigation have potential to improve experiences and outcomes for hospitalized children and their families.

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