

## Social Disadvantage, Access to Care, and Disparities in Physical Functioning Among Children Hospitalized with Respiratory Illness

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**BACKGROUND AND OBJECTIVES:** Understanding disparities in child health-related quality of life (HRQoL) may reveal opportunities for targeted improvement. This study examined associations between social disadvantage, access to care, and child physical functioning before and after hospitalization for acute respiratory illness.

**METHODS:** From July 1, 2014, to June 30, 2016, children ages 8-16 years and/or caregivers of children 2 weeks to 16 years admitted to five tertiary care children's hospitals for three common respiratory illnesses completed a survey on admission and within 2 to 8 weeks after discharge. Survey items assessed social disadvantage (minority race/ethnicity, limited English proficiency, low education, and low income), difficulty/delays accessing care, and baseline and follow-up HRQoL physical functioning using the Pediatric Quality of Life Inventory (PedsQL, range 0-100). We examined associations between these three variables at baseline and follow-up using multivariable, mixed-effects

linear regression models with multiple imputation sensitivity analyses for missing data.

**RESULTS:** A total of 1,325 patients and/or their caregivers completed both PedsQL assessments. Adjusted mean baseline PedsQL scores were significantly lower for patients with social disadvantage markers, compared with those of patients with none (78.7 for >3 markers versus 85.5 for no markers, difference -6.1 points (95% CI: -8.7, -3.5). The number of social disadvantage markers was not associated with mean follow-up PedsQL scores. Difficulty/delays accessing care were associated with lower PedsQL scores at both time points, but it was not a significant effect modifier between social disadvantage and PedsQL scores.

**CONCLUSIONS:** Having social disadvantage markers or difficulty/delays accessing care was associated with lower baseline physical functioning; however, differences were reduced after hospital discharge. *Journal of Hospital Medicine* 2020;15:211-218. © 2020 Society of Hospital Medicine

Examining disparities in health-related quality of life (HRQoL) outcomes in children provides a unique patient-centered perspective on pediatric health services equity.<sup>1,2</sup> Prior studies have demonstrated the relationship between minority race, low socioeconomic status, and lower maternal education with poorer HRQoL outcomes in children.<sup>3-6</sup> Some studies have also shown a dose-response relationship between social disadvantage markers and poorer child health status.<sup>7,8</sup> Furthermore, the associations between social disadvantage and poor access to care,<sup>9-11</sup> and between poor access to care and lower HRQoL, are also well established.<sup>12-14</sup>

Examining HRQoL before and after hospitalization can further our understanding of how disparities in HRQoL may change once children engage with the medical system for an acute illness.<sup>15</sup> Children requiring hospitalization constitute a useful population for examination of this question as they represent a group of children with variable social disadvantage markers and access to outpatient care.<sup>16</sup> Although interventions to address social determinants of health for patients with social disadvantages have been associated with within-group improvements in HRQoL, none have assessed changes in disparities as an outcome.<sup>17</sup> Furthermore, many of these studies were conducted in the outpatient setting,<sup>18,19</sup> whereas hospitalization provides an additional point of care to address the social determinants of health for vulnerable families.<sup>20</sup> Even for short hospitalizations, the 24/7 nature of hospital care provides the opportunity for frequent interactions with clinicians, nurses, and support staff to clarify illness-related questions, discuss other health concerns and unmet needs, and connect with social services or community resources. These opportunities may be particularly important for families with a higher number of social disadvantage markers and even more beneficial to

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those with difficulty accessing needed care from their primary medical home.

In this study, we focused on children with common respiratory illnesses (asthma, bronchiolitis, and pneumonia), which constitute the majority of childhood hospitalizations.<sup>21</sup> Additionally, we only focused on the child's physical functioning component of HRQoL because this component is most likely to improve after hospitalization for children with an acute respiratory illness.<sup>22</sup> A prior study examining HRQoL before and after hospitalization demonstrated that most children return to and/or surpass their baseline physical functioning by 1 month after hospital discharge.<sup>23</sup>

Our primary objective was to examine associations between several markers of social disadvantage, access to care, and child physical functioning before and after hospitalization for acute respiratory illness. Second, we aimed to understand if access to care (defined as perceived difficulty/delays getting care) acts as an independent predictor of improvement in physical functioning from baseline to follow-up and/or if it modifies the relationship between social disadvantage and improvement in physical functioning.

## METHODS

### Study Design and Population

This study was nested within a multicenter, prospective cohort study of children who were hospitalized for asthma, bronchiolitis, or pneumonia between July 2014 and June 2016 at one of five children's hospitals in the Pediatric Research in Inpatient Settings Network.<sup>24</sup>

We approached families for study participation within 72 hours of admission to the hospital using a standard protocol. Patients and their caregivers were eligible to participate in the study if the patient was 2 weeks to 16 years old and if the primary caregiver's preferred language for medical communication was either English or Spanish. Patients with chronic medical conditions (except asthma), with moderate to severe developmental delay, with a history of prematurity <32 weeks, or who received care in the intensive care unit were excluded. Patients could only participate in the study once.

The study team set out to enroll an even number of patients across all three conditions. If a patient's discharge diagnosis differed from their admission diagnosis (eg, from bronchiolitis to pneumonia), discharge diagnosis was used for condition group assignment. If the discharge diagnosis was not one of these three respiratory conditions, we excluded the patient from further analysis.

### Data Collection

We collected data using two surveys. The first survey was administered within 72 hours of admission. This survey asked questions related to (1) caregiver-reported markers of social disadvantage, (2) caregiver perceptions of access to care, and (3) caregiver- and patient-reported assessments of physical functioning. The second survey was administered within 2 to 8 weeks after the patient's discharge and included a second assessment of physical functioning.

### Social Disadvantage

Patients were considered to have a marker of social disadvantage if their caregiver reported (1) being of non-White race and/or Hispanic ethnicity, (2) primarily speaking a language other than English at home and not speaking English very well (ie, limited English proficiency), (3) attaining at most a high school or equivalent degree, or (4) having a  $\leq$ \$30,000 annual household income.

### Access to Care

We used the following survey item from the 2009-2010 National Survey of Children with Special Health Care Needs<sup>25</sup> to measure caregiver perceptions of access to care: "In the last six months, did you have any difficulties or delays getting care for your child because there were waiting lists, backlogs, or other problems getting an appointment?" We narrowed the original assessment time frame from 12 months to 6 months to provide a more proximal assessment of access in relation to the hospitalization.

### Child Physical Functioning

We assessed child physical functioning using the physical functioning domain of the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales and PedsQL Infant Scales, which have been validated for use in the inpatient setting.<sup>22</sup> Caregivers completed one of these scales based on their child's age. Assenting patients 8 to 16 years old completed the self-report PedsQL 4.0 Generic Core Scales instrument. When completing the first PedsQL survey, caregivers and patients reflected on the previous month before their child (or they) became ill to obtain a *baseline* physical functioning assessment.<sup>23</sup> When completing the second PedsQL survey, caregivers and patients reflected on the past 7 days to obtain a *follow-up* assessment.

All study procedures were approved by the Western Institutional Review Board (IRB) or the participating hospitals' IRB.

### Statistical Analysis

Patients with no missing data for all four social disadvantage markers were categorized based on the number of markers they reported: none, one, two, or three or more markers. We combined patients with three and four social disadvantage markers into one group to maximize power for the analyses. We dichotomized the access to care variable and coded response options as "no difficulty/delays accessing care" if the caregiver chose "Never" and "any difficulty/delays accessing care" if they chose "Sometimes/Usually/Always."

For each patient-caregiver dyad, PedsQL items were scored using a standard method in which higher scores reflected better functioning.<sup>22</sup> A single set of PedsQL scores was used for each patient-caregiver dyad. We used self-reported patient scores if the patient completed the PedsQL instrument; otherwise, we used proxy-reported caregiver scores. Intraclass correlations between child self-report and parent proxy-report demonstrate moderate to good agreement above age 8 years.<sup>26</sup> We computed a change in the physical functioning

score by subtracting the baseline score from the follow-up score. The minimal clinically important difference (MCID) for the PedsQL instrument is 4.5 points, which we used to identify clinically meaningful differences.<sup>13</sup>

Analysis of variance models were constructed to test for differences in mean baseline and follow-up PedsQL scores (dependent variable) between the following independent variables: (1) social disadvantage groups and (2) those who reported having any difficulty/delays accessing care compared with those who did not. Only patient–caregiver dyads with both baseline and follow-up assessments were included in these analyses. Mixed-effects linear regression models were constructed to identify clinically meaningful differences in PedsQL scores between groups (MCID  $\geq 4.5$ ) with adjustment for patient age, gender, respiratory condition, days between surveys, and hospital site as fixed effects. Site-specific random effects were included to account for within-hospital clustering. A similarly adjusted mixed-effects linear regression model was constructed to examine whether having any difficulty/delays accessing care modified the association between social disadvantage and PedsQL *change* scores (eg, an improvement from baseline to follow-up).

Because 17% of respondents had missing data for at least one social disadvantage marker, sensitivity analyses were conducted using multiple imputation to account for missing social disadvantage markers using chained equations.<sup>27</sup> Sensitivity analyses were also conducted to adjust for severity of illness using vital sign data within the first 24 hours, which could only be validly captured on patients with asthma within our dataset. By restricting this latter analysis to patients with asthma, we were able to examine the relationships of interest in a population with chronic disease.

## RESULTS

The study sample included 1,860 patients, of which 1,325 had both baseline and follow-up PedsQL data (71%). Descriptive statistics were similar between those who completed the baseline and follow-up surveys (Table 1).

Twenty-two percent of patients had  $\geq 3$  social disadvantages and 30% of caregivers reported having any difficulty/delays accessing care. The mean follow-up PedsQL score was higher than the baseline score (90.4 vs 82.5; Table 1).

### Social Disadvantage Markers and PedsQL Scores

The number of social disadvantage markers was inversely related to mean *baseline* PedsQL scores, but there was no difference in mean *follow-up* PedsQL scores between social disadvantage groups (Table 2). In adjusted analyses, the mean *baseline* PedsQL score was  $-6.1$  points (95% CI:  $-8.7, -3.5$ ) lower for patients with  $\geq 3$  social disadvantage markers compared with patients with no social disadvantage markers, which exceeded the scale's MCID.

### Difficulty/Delays Accessing Care and PedsQL Scores

Having any difficulty/delays accessing care was significantly associated with lower *baseline* and *follow-up* PedsQL scores (Ta-

ble 2). In adjusted analyses, the difference in *baseline* scores was 5.2 points (95% CI:  $-7.2, -3.2$ ), which exceeds the scale's MCID.

### Interaction Between Social Disadvantage Markers, Difficulty/Delays Accessing Care, and Change in PedsQL Scores from Baseline to Follow-up

While having  $\geq 2$  social disadvantage markers and difficulty/delays accessing care were each positively associated with changes in PedsQL scores from baseline to follow-up (Table 3), only patients with  $\geq 3$  social disadvantage markers exceeded the PedsQL MCID. In stratified analyses, patients with a combination of social disadvantage markers *and* difficulties/delays accessing care had lower *baseline* PedsQL scores and greater *change* in PedsQL scores from baseline to follow-up compared with those without difficulties/delays accessing care (Figure). However, having any difficulty/delays accessing care did not significantly modify the relationship between social disadvantage and change in PedsQL scores, as none of the interaction terms were significant (Table 3, Model 3).

### Sensitivity Analysis

Baseline, follow-up, and change in PedsQL scores were similar to our main analysis after performing multiple imputation for missing social disadvantage markers. Findings were also similar for patients with a diagnosis of asthma only; however, *changes* in PedsQL scores were greater in magnitude.

## DISCUSSION

This study examined the relationship between social disadvantage and child physical functioning before and after hospitalization for acute respiratory illness. Study findings indicated that patients with higher numbers of social disadvantage markers reported lower PedsQL scores before hospitalization; however, differences in PedsQL scores were not apparent after hospitalization. Patients who experienced difficulty/delays accessing care also reported lower PedsQL scores at baseline. This difference was still significant but did not exceed the PedsQL MCID threshold after hospitalization. Difficulty/delays accessing care appeared to be an additional social disadvantage marker; however, it did not modify the relationship between social disadvantage and improvement in physical functioning.

The study findings at baseline are consistent with prior studies demonstrating a negative association between social disadvantage markers and HRQoL and a cumulative effect based on the number of social disadvantages.<sup>3,4,7,8</sup> This study adds to the existing literature by examining how this relationship changes after hospitalization. As evidenced by the lack of association between social disadvantage markers and follow-up PedsQL scores, our findings suggest that receipt of inpatient care improved perceptions of physical functioning to a greater extent for patients with more social disadvantage markers (especially patients with  $\geq 3$  social disadvantage markers). There are several potential reasons for these findings.

One possibility is that caregivers and/or patients with more social disadvantage markers are more influenced by context

TABLE 1. Patient Demographics and Descriptive Statistics

Characteristics	Baseline Physical Functioning Assessment		Follow-Up Physical Functioning Assessment	
	No. of Responses <sup>a</sup>	No. (%) <sup>b</sup>	No. of Responses <sup>a</sup>	No. (%) <sup>b</sup>
Patient age (years)	1,860		1,326	
0-2		1,012 (54)		735 (55)
3-5		371 (20)		255 (19)
6-12		402 (22)		288 (22)
13-18		75 (4)		48 (4)
Patient sex	1,799		1,292	
Male		1,049 (58)		753 (58)
Female		750 (42)		539 (42)
Respiratory condition group	1,860		1,326	
Asthma		635 (34)		430 (32)
Bronchiolitis		696 (37)		507 (38)
Pneumonia		529 (28)		389 (29)
Type of social disadvantage				
Non-White race/ethnicity	1,828	1,066 (58)	1,304	733 (56)
Limited English proficiency	1,848	216 (12)	1,317	175 (13)
≤ High school or equivalent degree	1,841	648 (35)	1,312	426 (32)
≤ \$30k annual household income	1,560	631 (40)	1,127	432 (38)
No. of social disadvantages	1,536		1,110	
0		491 (32)		390 (35)
1		401 (26)		283 (26)
2		309 (20)		205 (18)
3		260 (17)		171 (15)
4		75 (5)		61 (6)
Child had healthcare provider visit in the past 6 months?	1,858		1,325	
Yes		1,655 (89)		1,191 (90)
No		203 (11)		134 (10)
Access to care	1,648		1,185	
No difficulty/delays accessing care		1,148 (70)		838 (71)
Any difficulty/delays accessing care		500 (30)		347 (29)
	<b>No. of Responses</b>	<b>Mean (SD)</b>	<b>No. of Responses</b>	<b>Mean (SD)</b>
PedsQL Physical Functioning Score	1,858	82.5 (15.5)	1325	90.4 (13.4)

<sup>a</sup>The number of observations in each category diverges from the total number in full cohort because of missing data.

<sup>b</sup>Proportions may diverge from 100% due to rounding.

Abbreviations: PedsQL, Pediatric Quality of Life Inventory; SD, standard deviation.

when assessing physical functioning. This could lead to an underestimation of functioning when asked to recall baseline physical functioning at the time of acute illness and overestimation of functioning after recovery from an illness. This possibility is consistent with a form of response bias, extreme response tendencies, in which lower socioeconomic subgroups tend to choose the more extreme response options of a scale.<sup>28</sup> In the absence of longitudinal assessments of HRQoL across the care continuum over time, disentangling whether these differences are due to response bias or representative of true changes in

physical functioning remains challenging.

Given that disparities in physical functioning at baseline were consistent with prior evidence, another possibility is that hospitalization provided an opportunity to address gaps in access and quality that may have existed for patients with social disadvantage in the community setting. The 24/7 nature of hospital care, usually from a multidisciplinary team of providers, lends itself to opportunities to receive intensive education related to the current illness or to address other health concerns that parents or providers identify during a hospital stay.

TABLE 2. Observed Means for PedsQL Physical Functioning Scores by Number of Social Disadvantage Markers and Difficulty/Delays Accessing Outpatient Care Before and After Receiving ED/Hospital Care

No. of Social Disadvantages	No. <sup>a</sup>	Baseline PedsQL Physical Functioning Score	Follow-up PedsQL Physical Functioning Score	Change in PedsQL Physical Functioning Score
		Mean (SD)	Mean (SD)	Mean (SD)
0	390	85.5 (12.9)	90.4 (12.9)	+4.9 (15.6)
1	283	83.6 (14.2)	90.0 (13.5)	+6.5 (16.3)
2	205	82.4 (15.4)	90.6 (13.2)	+8.2 (15.8)
≥3	232	78.7 (17.9) <sup>b</sup>	90.9 (13.8)	+12.2 (17.2)
Overall	1,110	83.0 (15.1)	90.8 (13.3)	+7.5 (16.4)
ANOVA P value		<.001	.91	<.001
<b>Difficulty/Delays Accessing Care</b>				
No difficulty/delay	838	83.8 (14.4)	91.0 (13.0)	+7.1 (16.2)
Any difficulty/delay	347	78.4 (16.8) <sup>c</sup>	88.5 (14.8)	+10.1 (17.7)
Overall	1,185	82.2 (15.3)	90.2 (13.6)	+8.0 (16.7)
ANOVA P value		<.001	<.01	<.01

<sup>a</sup>Only includes patients who completed both the baseline and follow-up PedsQL assessments.

<sup>b</sup>Difference in score from the score of those with no social disadvantage markers exceeded the PedsQL minimal clinically important difference of 4.5 points.

<sup>c</sup>Difference in score from the score of those with no difficulty/delays accessing care exceeded the PedsQL minimal clinically important difference of 4.5 points.

Abbreviations: ANOVA, analysis of variance; PedsQL, Pediatric Quality of Life Inventory; SD, standard deviation.

TABLE 3. Adjusted Associations Between Social Disadvantage, Difficulty/Delay Accessing Outpatient Care and Change in PedsQL Physical Functioning Scores from Baseline to Follow-up

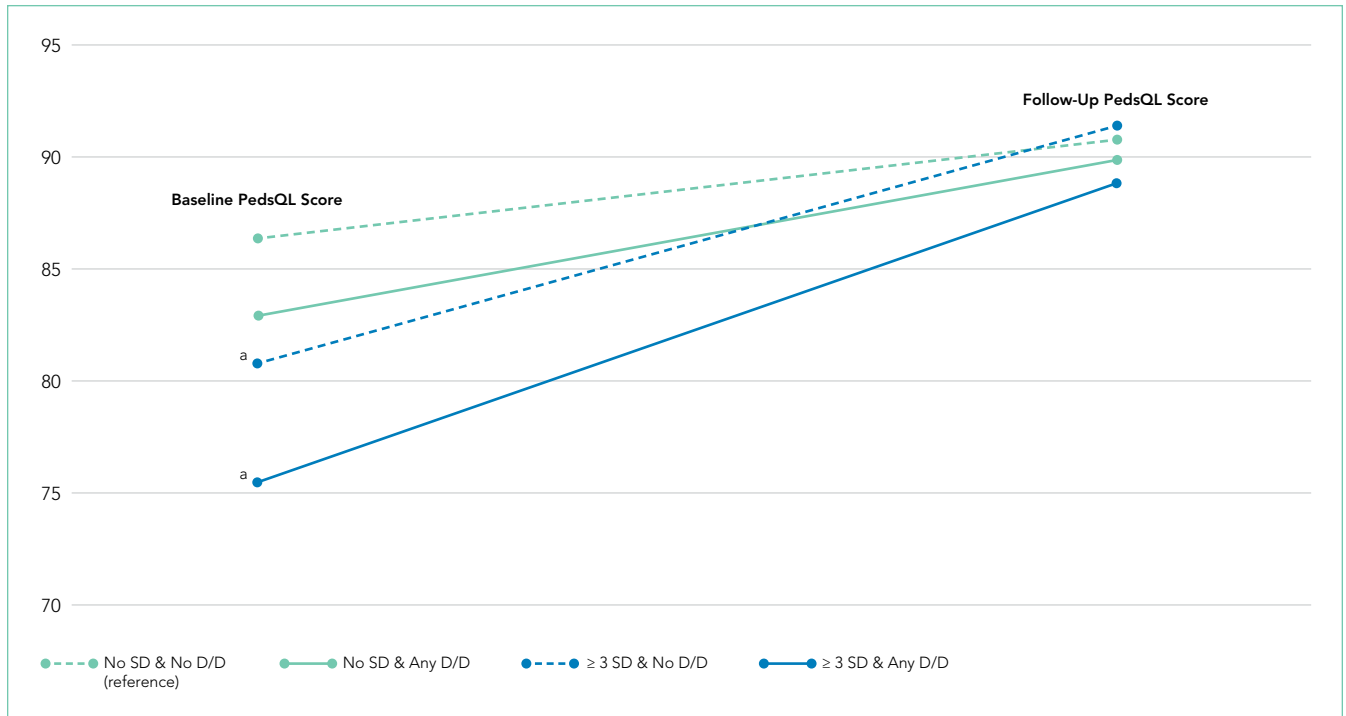
Predictor of interest	Change in PedsQL Physical Functioning Score		
	Model 1 <sup>a</sup> β (95% CI) <sup>b</sup>	Model 2 <sup>a</sup> β (95% CI) <sup>b</sup>	Model 3 <sup>a</sup> β (95% CI) <sup>b</sup>
No. of Social Disadvantages			
0	Ref		Ref
1	0.9 (−1.8, 3.2)		0.6 (−1.6, 2.8)
2	2.3 (0.0, 4.7)*		2.3 (1.0, 3.7)**
≥3	6.1 (4.6, 7.7)***		6.9 (4.3, 9.5)***
Difficulty/Delay Accessing Care			
None		Ref	Ref
Any D/D		2.4 (0.2, 4.6)*	2.9 (2.2, 3.6)***
Interaction			
Any D/D × 1 social disadvantage			−0.9 (−5.0, 3.1)
Any D/D × 2 social disadvantages			−1.3 (−4.9, 2.3)
Any D/D × ≥3 social disadvantages			−2.0 (−5.3, 1.3)

\*P < .05; \*\*P < .01; \*\*\*P < .001.

<sup>a</sup>Models 1-3 are adjusted for patient age, gender, respiratory condition, days between surveys, hospital site, and clustering by site. Model 1 only had social disadvantage as the main effect; Model 2 only had difficulty/delays accessing care as the main effect; and Model 3 had social disadvantage, difficulty/delays accessing care, and their interaction as the main effects.

<sup>b</sup>Regression coefficients represent the difference in PedsQL change score from the reference category, where clinically meaningful differences are >4.5 points based on the minimal clinically important difference on the PedsQL instrument.

Abbreviations: β, regression coefficient; D/D, difficulty/delays accessing care; PedsQL, Pediatric Quality of Life Inventory.



**FIG.** Observed Change in PedsQL Physical Functioning Scores from Baseline to Follow-up.

<sup>a</sup> Indicates the difference in PedsQL score from the reference score exceeded the PedsQL minimal clinically important difference of 4.5 points. Abbreviations: D/D, difficulties/delays accessing outpatient care; PedsQL, Pediatric Quality of Life Inventory; SD, social disadvantage markers.

For example, consistent and repetitive asthma education may be more beneficial to patients and families with more social disadvantage markers. The fact that the association between social disadvantage markers and change in physical functioning scores were greater for patients with asthma supports this reasoning. Hospital care may also provide an opportunity to address other unmet medical needs or psychosocial needs by providing efficient access to subspecialists, social workers, or interpreters. Further research is needed to elucidate whether families received additional services in the hospital setting that were not available to them prior to hospitalization, such as consistent interpreter use, social work engagement, and subspecialty/community referrals. Further studies should also determine whether the provision of equitable medical and social support services is associated with improvements in HRQoL disparities. Additionally, studies should examine whether physical functioning improvements following hospitalization return to baseline levels after a longer period of time and, if so, how we might sustain these reductions in HRQoL disparities. Such studies may identify tangible targets and interventions to reduce disparities in HRQoL for these children.

This study highlights the importance of assessing for difficulty/delays accessing care in addition to social disadvantage markers, as this was also a significant predictor of lower child physical functioning. Differences in PedsQL scores between those who reported any versus no difficulty/delays accessing care were more pronounced at baseline compared with follow-up. A possible reason for these findings is that receiving hospital care may have addressed some access to care issues

that were present in the outpatient setting, which resulted in improved perceptions of physical functioning. For example, hospital care may mitigate access to care barriers such as limited after-hours clinic appointments, language barriers, and lack of insurance, thus providing some patients with an alternative pathway to address their health concerns. Alternatively, hospital staff may assist families in scheduling follow-up appointments with the patient’s primary medical home after discharge, which potentially reduced some access to care barriers. The question is whether these disparities will widen once again after a longer follow-up period if families continue facing barriers to accessing needed care in the outpatient setting.

The results of the effect modification analysis demonstrated that the association between social disadvantage and change in PedsQL scores from baseline to follow-up was not significantly different based on a child’s ability to access care. In our stratified analysis, difficulty/delays accessing care added to baseline disparities at each social disadvantage level but did not alter how perceptions of physical functioning change over time. Therefore, physical functioning improvements may rely more heavily on the type of care received within the hospital setting as opposed to accessing care in the first place. However, future studies should examine whether access to high-quality care instead of simply measuring difficulty/delays in accessing care would lead to different results. Access to a comprehensive medical home may be a better measure to assess for effect modification because it measures features beyond access to care, such as continuity, comprehensiveness, communication, and coordination of outpatient care.<sup>29-31</sup>

If additional studies find evidence that the nature of hospital care, an intensive 24/7 care setting, differentially benefits patients with higher social disadvantage markers (particularly those with  $\geq 3$  markers and chronic illness), this would support the need for systematic screening for social disadvantages or difficulty/delays accessing care in the inpatient setting. Systematic screening could help ensure all patients who may benefit from additional services, such as intensive, culturally tailored education or connections to food, housing, or financial services, will in fact receive them, which may lead to sustained reductions in health disparities.<sup>20</sup> Further research into pairing validated screening tools with proven interventions is needed.<sup>32</sup>

This study has additional limitations aside from those noted above. First, we did not reassess perceived or actual access to care after hospitalization, which may have allowed for analyses to examine access to care as a mediator between social disadvantage and lower child physical functioning. Second, this study included only English- and Spanish-speaking patients and families. Patients with less commonly spoken languages may experience more difficulty accessing or navigating the health system, which may further impact access to care and HRQoL. Third, we had a considerable amount of missing social disadvantage marker data (mainly income); however, our sensitivity analyses did not result in significantly different or clinically meaningful differences in our findings. Insurance status is more feasible to obtain from administrative data and could serve as a proxy for income or as an additional social disadvantage marker in future studies. Finally, we could calculate illness severity only for patients with asthma based on the available data; therefore, we could not adequately control for illness severity across all conditions.

## CONCLUSIONS

Social disadvantage was associated with lower child physical functioning before hospitalization, but differences were not apparent after hospitalization for children with acute respiratory illness. Caregiver-perceived difficulty/delays accessing care was found to be an additional predictor of lower physical functioning at baseline but did not significantly alter the association between social disadvantage and improvement in physical functioning over time. Further studies are needed to understand how hospital care may differentially impact child physical functioning for patients with higher social disadvantage markers in order to sustain improvements in HRQoL disparities.

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