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Parental Health Literacy and Patient Clinical Outcomes in Juvenile Idiopathic Arthritis with a Health Equity Lens

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Abstract

Background/Objectives: Health literacy (HL) is the ability to obtain, understand, and use information to make health-related decisions. Its impact on rheumatologic outcomes remains unclear. We examined the relationship between parental HL and clinical outcomes of patients with juvenile idiopathic arthritis (JIA) at an ethnically diverse academic center. **Methods**: In this single-center cross-sectional study, parents of patients with JIA completed a demographic survey and the Newest Vital Sign (NVS), a validated six-item HL assessment. Parental HL was dichotomized into limited HL (NVS score 0–1) and possibly limited/adequate HL (NVS score 2–6). The clinical Juvenile Arthritis Disease Activity Score based on a ten-joint count (cJADAS10) and Patient-Reported Outcomes Measurement Information System (PROMIS) were used to determine clinical outcomes. Clinical characteristics and outcomes were compared, and odds of active disease (cJADAS10 > 1) were estimated. **Results**: Seventy-five parents participated, 15 (20.0%) had limited HL. Among patients with polyarticular disease, median cJADAS10 was higher in the limited HL group [8.0 (IQR 3.0–11.0), $n = 11$ vs. 2.2 (IQR 0.0–7.0), $n = 28$; $p = 0.017$]. Among patients with oligoarticular disease, PROMIS mobility scores were lower in the limited HL group [35.3 (IQR 27.1–45.4), $n = 4$ vs. 52.1 (IQR 52.1–52.9), $n = 30$; $p = 0.037$]. In an exploratory multivariable model, limited HL was associated with higher adjusted odds of active disease, although the estimate was imprecise (OR 6.96, 95% CI 1.19–40.81; $p = 0.031$). **Conclusions**: In this cross-sectional cohort, limited parental HL was associated with higher disease activity in polyarticular JIA and higher adjusted odds of active disease in an exploratory adjusted analysis.

Keywords: health literacy; juvenile idiopathic arthritis; clinical outcomes; health equity; social determinants of health

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1. Introduction

Juvenile idiopathic arthritis (JIA) is the most common primary rheumatologic condition that affects children, with a childhood arthritis prevalence of 305 per 100,000 US children and adolescents [1]. JIA outcomes have substantially improved since the introduction of biologic disease modifying antirheumatic drugs (bDMARDs) [2]. However, significant gaps remain in understanding how patient outcomes vary among racial and

ethnic backgrounds. A cross-sectional study of children with JIA enrolled in the Childhood Arthritis and Rheumatology Research Alliance (CARRA) registry found that African American children with polyarticular course had higher risk of joint damage compared to White children and that Hispanic children had increased odds of having disability scores higher than the 75th percentile compared to non-Hispanic/Latino children [3]. In a registry of 9601 JIA patients, Non-Hispanic Black patients had statistically higher cJADAS10 scores compared to non-Hispanic White patients [4].

In addition to ethnicity and race, social determinants of health influence clinical outcomes of patients with JIA. Another CARRA study demonstrated that lower household income was associated with higher disease activity and that public insurance and lower family education levels were associated with persistent functional disability [5]. Although some of the differences in outcomes and prognosis may be explained by the JIA subtype and the presence of certain biologic markers, such as higher prevalence of rheumatoid factor and polyarticular involvement in Hispanic American patients [6], studying how non-medical drivers influence the outcomes of patients with JIA is crucial to improve understanding and prioritize interventions.

Health literacy (HL) is an important non-medical driver of health that includes personal competencies and resources that are needed for individuals to access, understand, and use health information and services to make decisions about their health [7,8]. Health literacy is most often measured with brief validated screening instruments. The Newest Vital Sign (NVS), used in the present study, yields a score from 0 to 6, on which 0–1 indicates a high likelihood of limited HL, 2–3 the possibility of limited HL, and 4–6 adequate HL [9]. Poor parental health literacy has been associated with poorer health knowledge in studies of child health [10]. A systematic review of 57 studies of diabetes found 10 studies in which low HL was associated with worse glycemic control [11]. A 2010 study published in *Pediatrics* in which the NVS was used in 200 caregivers of patients with diabetes found that children whose caregivers had inadequate HL had higher hemoglobin A1C than those whose caregivers had adequate HL [12]. Low parental HL of children with chronic disease has also been associated with higher parental stress and anxiety [13]. Factors that influence limited HL in caregivers include foreign origin, limited educational attainment, younger caregiver age, and public insurance [14].

In pediatric rheumatology, Dogan et al. [15] evaluated HL in a Turkish population with JIA using the European Health Literacy Survey Questionnaire (HLS-EU-Q), on which the general health literacy index ranges from 0 to 50 and is categorized as inadequate (0–25), problematic (>25–33), sufficient (>33–42), and excellent (>42–50) [16]. Approximately a quarter of the parents scored in the inadequate or problematic range, and no association with health status or quality of life was observed. The HLS-EU-Q and the NVS assess different constructs and use different score bands that can be broadly comparable but not directly equivalent. In contrast, Lazaroff et al. demonstrated transition readiness in American young adults with rheumatologic conditions. The cohort was characterized by having adequate HL (98%), being White (78.6%), and completion of some college or technical school (66.7%), and almost a quarter of their households earned USD 100–150K per year [17].

Due to the chronic nature of rheumatologic disorders, patients and their families interact with the healthcare system on an ongoing basis. Limited HL may be a marker of, or a contributor to, health disparities in this population and may identify families for whom additional support is warranted. In this study, we explored the relationship between parental HL and health outcomes in a diverse population of patients with JIA.

2. Materials and Methods

2.1. Study Design and Setting

This was a single-center, cross-sectional study conducted at Texas Children's Hospital, a large tertiary academic pediatric medical center, and its affiliated satellite clinics. The study was approved by the Institutional Review Board of Baylor College of Medicine and conducted in accordance with the Declaration of Helsinki. Recruitment took place between April 2024 and February 2025. Both the exposure (parental HL) and the primary outcome (disease activity at the most recent visit) were ascertained at a single time point; disease activity measures and healthcare utilization data were abstracted retrospectively from the medical record.

2.2. Participants

Patients were eligible if all of the following applied: age 18 years or younger at the study visit, a diagnosis of persistent oligoarticular JIA (four or fewer joints ever involved) or polyarticular JIA (five or more joints ever involved) according to the International League of Associations for Rheumatology (ILAR) criteria, attendance at the rheumatology visit accompanied by a parent or legal guardian, and a parent or guardian able to complete the study instruments in English or Spanish. Patients were excluded if they had systemic JIA, extended oligoarticular JIA, juvenile psoriatic arthritis, enthesitis-related arthritis, or undifferentiated arthritis, if the accompanying parent or guardian's preferred language was neither English nor Spanish, or if the patient attended unaccompanied by a parent or guardian.

Each participant was assigned to exactly one subtype group based on the treating rheumatologist's documented ILAR classification. Because extended oligoarticular JIA is defined by initial involvement of four or fewer joints with subsequent progression to five or more and could therefore be classified under either heading, this subtype was excluded a priori rather than allocated to a subtype group. No participant contributed to more than one subtype group, and no participant's subtype classification changed during the study period. Rheumatology clinic schedules at Texas Children's Hospital medical center and its satellite clinics were reviewed weekly to identify potentially eligible patients, who were approached before or on the day of the rheumatology visit; eligibility was confirmed at screening. The number of families screened was not prospectively recorded. Electronic or written consent was obtained from every participating parent or guardian.

2.3. Measures

Social determinants of health were assessed using the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) tool [18,19]. For race, responders could choose "Hispanic or Latino" as a "yes or no" question. Individuals were asked to select all races that apply from Asian, Pacific Islander, White, Native Hawaiian, Black/African American, American Indian/Alaskan Native, and "other". Additional demographic information was obtained through a separate one-page survey that included age of parent, knowledge and use of Medicaid transportation, primary language spoken, and duration lived in the United States. The PRAPARE needs inventory covered food, clothing, utilities, childcare, healthcare, and telephone and offered "I choose not to answer this question" for every item.

Parental HL was assessed with the Newest Vital Sign (NVS), a six-item instrument assessing numeracy and comprehension using an ice cream nutrition label. Parents completed the NVS in their preferred language using the corresponding validated version. The instrument was administered verbally by the corresponding author (Y.P), a certified bilingual pediatric rheumatology fellow trained in standardized NVS administration and scoring according to the

published instrument manual. The nutrition label was presented to the parent in printed form while the six questions were read aloud in a private clinic room, and responses were recorded verbatim and scored immediately. The total score is the number of correct responses from 0 to 6; scores of 0–1 indicate a high likelihood of limited HL, 2–3 the possibility of limited HL, and 4–6 adequate HL [9]. For analysis, participants were dichotomized into a limited HL group (NVS 0–1) and a possibly limited/adequate HL group (NVS 2–6). Dichotomization was chosen because only 11 participants scored 2–3, too few to support a stable three-level comparison, and because the 0–1 band is the threshold at which the instrument's developers indicate a high likelihood of limited HL. This second group is referred to as "possibly limited/adequate HL" throughout, as it contains both participants with possible limited HL (NVS 2–3) and participants with adequate HL (NVS 4–6).

2.4. Chart Review and Extracted Variables

Chart review was performed by the corresponding author (Y.P.) using a standardized abstraction form with pre-specified variable definitions established before data collection began. The following variables were abstracted from the electronic medical record:

- Patient characteristics: Age at the study visit, sex, ILAR subtype, date of diagnosis, time from diagnosis to the study visit (6–12 months, >12 months to 2 years, >2 years), and time in months from symptom onset to the first rheumatology visit.
- Disease activity: cJADAS10 at diagnosis, 6 months, 12 months, and the most recent visit. Physician global assessment visual analogue scale, parent or patient global assessment visual analogue scale, and the active joint count documented in the chart were collected at the same time points.
- Treatment: Time to initiation of first conventional synthetic DMARD (csDMARD) and biological DMARD (bDMARD) was captured in weeks from the order date to the first documented administration of therapy (details on treatment were not documented). A steroid course was defined as a prescription of systemic glucocorticoid, oral or intravenous given for JIA disease activity. The number of courses was expressed as course per year since diagnosis. Intraarticular steroid injections were recorded separately.
- Healthcare utilization and engagement: Appointment attendance; number of emergency department visits in the six months preceding the study visit attributed by the corresponding author to JIA; patient portal (MyChart) activation and use; no-show rate across all primary care and subspecialty appointments; and documentation of medication nonadherence by a rheumatology provider in the six months preceding the study visit.

Two variables required clinical judgment: provider-documented medication nonadherence and the attribution of an emergency department visit to JIA. These two variables were abstracted by a single reviewer who was not blinded to the HL group, and no independent verification was performed; this is acknowledged as a limitation.

2.5. Outcomes

The primary outcome was disease activity based on cJADAS10 at the most recent visit. The cJADAS10 is a validated JIA outcome measure that includes three composite scores: the physician global assessment visual analog scale (VAS) of 0–10, parent/patient global assessment VAS of 0–10, and active joint count ranging from 0 to 10 [20,21]. Active disease was defined as cJADAS10 > 1 and inactive disease as cJADAS10 ≤ 1, consistent with the published threshold for clinically inactive disease [22]. Patient-reported outcomes were measured using the Patient-Reported Outcomes Measurement Information System (PROMIS). The PROMIS mobility and upper extremity tests involve a set of questions that evaluate functional mobility and have been adapted for children [23,24] as well as a parent

proxy version [25]. Mobility was analyzed as a single pre-specified composite measure in which the instrument used depended on the child's age: the Pediatric Mobility Short Form 7a for children aged 8 years or older and the Parent Proxy Mobility Short Form 7a for children younger than 8 years. Scores from the two component instruments are additionally reported separately as secondary descriptive information.

2.6. Sample Size

A sample size estimate was performed separately for each JIA subtype using published cJADAS10 disease activity state cut-offs separating minimal, moderate, and high disease activity. For oligoarticular disease, the cut-offs were 1.5, 2.5, and 4.0 and for polyarticular disease 2.5, 4.5, and 8.5 [26]. The sample size calculation was based on the Kruskal–Wallis test, which compared the median values between the 3 groups. We estimated that 36 oligoarticular and 15 polyarticular patients would be required to have 80% power.

2.7. Statistical Analysis

All baseline characteristics were summarized with descriptive statistics. Characteristics and clinical outcomes were compared in two HL groups, limited HL (NVS score of 0–1) and possibly limited/adequate HL (score of 2–6). Continuous variables are summarized as median (interquartile range) and categorical variables as *n* (%), with the denominator of non-missing observations given wherever it differs from the group total. Continuous and ordinal variables were compared between the two health literacy groups using the Wilcoxon rank-sum test. Categorical variables were compared using Pearson's chi-square test or Fisher's exact test where any expected cell count was below five, and a single overall *p*-value is reported for the variable. All tests were two-sided, and no adjustment was made for multiple comparisons.

Multivariable logistic regression was used to estimate the association between parental health literacy and active disease (cJADAS10 > 1). Covariates were selected as a priori, and the model was not modified after inspection of the results. The model contained parental health literacy group (limited HL versus possibly limited/adequate HL), insurance type (none, public non-CHIP, public CHIP, private), survey language (Spanish versus English), documented medication nonadherence (present versus absent), and JIA subtype (polyarticular versus oligoarticular). Hispanic ethnicity was not included in the multivariable model because of its collinearity with survey language. All statistical analyses were performed using Stata v 18.1 (StataCorp, College Station, TX, USA).

3. Results

3.1. Participants and Baseline Characteristics

Ninety-two patients were identified from the clinic schedules as potentially eligible and were approached. Of these, 14 were excluded at screening (13 because their JIA subtype was not persistent oligoarticular or polyarticular JIA and 1 because the patient attended without a parent or guardian), leaving 78 eligible patients. Out of the 78, 3 (3.8%) declined participation, and 75 (96.2%) were enrolled. Of the 75 participating parents, 15 (20%) had limited HL (NVS 0–1), 11 (14.7%) possible limited HL (NVS 2–3), and 49 (65.3%) adequate HL (NVS 4–6). Table 1 summarizes the baseline demographics of our study population. Median age of patients was 10 (IQR 7–14; $n = 75$), 36 out of 75 (48.0%) had oligoarticular and 39 out of 75 (52.0%) polyarticular subtype, and 54 out of 75 (72.0%) had been diagnosed more than 2 years before the study visit. Among parents, 48 out of 75 (64.0%) reported White race, 34 out of 73 (46.6%) Hispanic ethnicity, and 22 out of 75 (29.3%) completed the survey in Spanish. A patient portal account was active for 74 out of 75 patients (98.7%), and there was evidence of its use (e.g., patient messages, refill requests) in 71 out of 74

(95.9%) patients. Median cJADAS10 at the most recent visit was 2.0 (IQR 0.0–6.0; $n = 69$), and 36 out of 69 patients (52.2%) had active disease.

Table 1. Demographics and social characteristics by parental health literacy group.

Characteristics	*n* with Data	Total	Limited HL ($n = 15$)	Possibly Limited/Adequate HL ($n = 60$)	*p*
JIA subtype	75				0.086
Oligoarticular		36 (48)	4 (26.7)	32 (53.3)	
Polyarticular		39 (52)	11 (73.3)	28 (46.7)	
Time since diagnosis	75				0.813
6–12 months		10 (13.3)	2 (13.3)	8 (13.3)	
>12 months to 2 years		11 (14.7)	3 (20.0)	8 (13.3)	
>2 years		54 (72)	10 (66.7)	44 (73.3)	
Patient age, years, median (IQR)	75	10 (7.0,14.0)	10 (7.0, 15.0)	10.5 (7.0, 14.0)	0.926
Parent/guardian age	74				0.660
21–30		6 (8.1)	2 (13.3)	4 (6.8)	
31–40		33 (44.6)	6 (40.0)	27 (45.8)	
41–50		29 (39.2)	7 (46.7)	22 (37.3)	
51–60		5 (6.8)	0 (0.0)	5 (8.5)	
61–70		1 (1.4)	0 (0.0)	1 (1.7)	
Language	75				<0.001 *
Spanish		22 (29.3)	11 (73.3)	11 (18.3)	
English		53 (70.7)	4 (26.7)	49 (81.7)	
Race **	75				
White		48 (64)	5 (33.3)	43 (71.7)	0.014 *
Asian		7 (9.3)	1 (6.7)	6 (10.0)	>0.99
Black		6 (8)	1 (6.7)	5 (8.3)	>0.99
Other †		8 (10.7)	5 (33.3)	3 (5.0)	0.007 *
Choose not to answer		6 (8)	3 (20.0)	3 (5.0)	0.090
Hispanic ethnicity	73				0.007 *
Yes		34 (46.6)	12 (80)	22 (37.9)	
No		39 (53.4)	3 (20)	36 (62.1)	
Time living in USA	74				0.029 *
1–5 years		7 (9.5)	4 (26.7)	3 (5.1)	
6–10 years		3 (4.1)	1 (6.7)	2 (3.4)	
>10 years		64 (86.5)	10 (66.7)	54 (91.5)	
Heritage/region ‡	37				0.247 *
Mexico		11 (29.7)	2 (15.4)	9 (37.5)	
Central America		13 (35.1)	7 (53.8)	6 (25.0)	
South America		2 (5.4)	0 (0.0)	2 (8.3)	
Other		11 (29.7)	4 (30.8)	7 (29.2)	
Annual household income, USD, median (IQR)	43	100,000 (40,000–200,000)	35,000 (33,600–40,000) $n = 5$	100,000 (50,000–200,000) $n = 38$	0.039 *
Parental education	73		$n = 15$	$n = 58$	<0.001 *
Less than high school		8 (11)	6 (40.0)	2 (3.4)	
High school or GED		16 (21.9)	5 (33.3)	11 (19.0)	
More than high school		48 (65.8)	3 (20.0)	45 (77.6)	
Choose not to answer		1 (1.4)	1 (6.7)	0 (0.0)	
Work situation	73		$n = 15$	$n = 58$	0.215
Unemployed		11 (15.1)	5 (33.3)	6 (10.3)	

Table 1. *Cont.*

Characteristics	*n* with Data	Total	Limited HL (*n* = 15)	Possibly Limited/Adequate HL (*n* = 60)	*p*
Part time		10 (13.7)	2 (13.3)	8 (13.8)	
Full time		42 (57.5)	6 (40.0)	36 (62.1)	
Unemployed but not seeking		8 (11.0)	2 (13.3)	6 (10.3)	
Choose not to answer		2 (2.7)	0 (0.0)	2 (3.4)	
Insurance	73				0.001 *
None		10 (13.7)	6 (40.0)	4 (6.9)	
Public non-Chip		23 (31.5)	7 (46.7)	16 (27.6)	
Public CHIP		2 (2.7)	0 (0.0)	2 (3.4)	
Private insurance		38 (52.1)	2 (13.3)	36 (62.1)	
PRAPARE item 14 * **	75				0.002 *
One or more needs reported		13 (17.3)	5 (33.3)	8 (13.3)	
No needs reported		52 (69.3)	5 (33.3)	47 (78.3)	
Choose not to answer		10 (13.3)	5 (33.3)	5 (8.3)	
Transportation difficulties	75	3 (4)	2 (13.3)	1 (1.7)	0.100
Support system contact	73		*n* = 15	*n* = 58	0.0001 *
<once a week		7 (9.6)	2 (13.3)	5 (8.6)	
1 or 2 times a week		13 (17.8)	2 (13.3)	11 (19.0)	
3 to 5 times a week		11 (15.1)	4 (26.7)	7 (12.1)	
5 or >times a week		35 (47.9)	2 (13.3)	33 (56.9)	
Choose not to answer		7 (9.6)	5 (33.3)	2 (3.4)	
csDMARD	75	45 (60)	9 (60)	36 (60)	0.999
bDMARD	75	42 (56)	10 (66.7)	32 (53.3)	0.398

Values are *n* (%) unless otherwise stated. Percentages are calculated on the number with non-missing data for each variable, shown in the second column. Limited HL: Newest Vital Sign (NVS) score 0–1. Possibly limited/adequate HL: NVS score 2–6. ** For race, respondents could choose more than one option. † Other race refers to Pacific Islander, Native Hawaiian, or American Indian/Alaskan Native. ‡ Heritage/region item was asked only of respondents who selected Spanish as their primary language. GED: General Educational Development; CHIP: Children's Health Insurance Program; PRAPARE: Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences; csDMARD: Conventional Synthetic Disease Modifying Anti-Rheumatic Drug; bDMARD Biologic Disease Modifying Anti-Rheumatic Drug. * $p < 0.05$ *** Item 14 in PRAPARE asks if the respondent has needs in multiple areas, including food and clothing, as "yes or no" for each item. "No needs reported" refers to when they choose "no" for all items.

Parental age, patient age, and time since diagnosis were similarly distributed among groups. Possibly limited/adequate HL was significantly associated with English language, White race, living in the United States for 10 years or more, higher education, private insurance, higher income, and seeing a loved one five or more times per week. Parents in the limited HL group were more likely to have completed the survey in Spanish [11 out of 15 (73.3%) vs. 11 out of 60 (18.3%); risk difference +55.0 percentage points, 95% CI +30.6 to +79.4; $p < 0.001$], to report Hispanic ethnicity [12 out of 15 (80.0%) vs. 22 out of 58 (37.9%); risk difference +42.1 percentage points, 95% CI +18.3 to +65.9; $p = 0.007$], to have less than a high school education [6 out of 14 (42.9%) vs. 2 out of 58 (3.4%); risk difference +39.4 percentage points, 95% CI +13.1 to +65.8; $p < 0.001$], and to be uninsured [6 out of 15 (40.0%) vs. 4 out of 58 (6.9%); risk difference +33.1 percentage points, 95% CI +7.5 to +58.7; $p = 0.004$].

Parents in the limited HL group were more likely both to report one or more unmet needs [5 of 15 (33.3%) vs. 8 of 60 (13.3%)] and to decline to answer the item [5 of 15 (33.3%) vs. 5 of 60 (8.3%)]. Because this non-response was differential by HL group, the

prevalence of unmet needs in the limited HL group is likely to be understated. There was no difference in household size, homelessness, worry about losing housing, use of Medicaid transportation, specific needs, or frequency of feeling anxious or stressed. There was no significant difference in time to initiation of csDMARD or bDMARD among HL groups, and there was no difference in the percentage of patients who were started on csDMARD vs. bDMARD.

3.2. Outcomes by Health Literacy Group

Table 2a summarizes outcomes by HL group. Polyarticular and oligoarticular groups were evaluated separately for outcomes that were influenced by joint count. For polyarticular patients, median cJADAS10 was significantly higher in patients whose parents had limited HL [median cJADAS10 8.0 (IQR 3.0–11.0), $n = 11$ vs. 2.2 (IQR 0.0–7.0), $n = 28$; $p = 0.017$]. Inactive disease was present in 1 out of 10 (10.0%) in the limited HL group vs. 13 out of 28 (46.4%) in the possibly limited/adequate HL group [risk difference for active disease +36.4 percentage points, 95% CI +10.2 to +62.6; OR 7.80, 95% CI 0.87–70.08; $p = 0.059$]. There was no significant difference in mobility scores, number of steroid courses, or joint count at presentation at 6 months or 12 months from diagnosis.

For oligoarticular patients, median cJADAS10 was higher in the limited HL group, but the difference was not statistically significant [4.2 (IQR 1.5–7.8), $n = 4$ vs. 0.0 (IQR 0.0–2.0), $n = 27$; $p = 0.149$]. Scores on the pre-specified composite PROMIS mobility measure were lower in oligoarticular patients in the limited HL group [35.3 (IQR 27.1–45.4), $n = 4$ vs. 52.1 (IQR 52.1–52.9), $n = 30$; $p = 0.037$]; this comparison rests on four patients in the limited HL group. Inactive disease was present in 1 out of 4 (25.0%) in the limited HL group vs. 18 out of 27 (66.7%) in the possibly limited/adequate HL group [risk difference for active disease +41.7 percentage points, 95% CI −4.3 to +87.7; $p = 0.272$]. There was no difference in the number of steroid courses or joint count at different time points in oligoarticular patients.

Table 2. (**a**) Clinical outcomes by parental health literacy group, stratified by JIA subtype. (**b**) Whole-cohort outcomes by parental health literacy group.

(**a**)

Outcome	Polyarticular Limited HL *n*= 11	Polyarticular Possibly Limited/Adequate HL *n*= 28	*p*	Oligoarticular Limited HL *n*= 4	Oligoarticular Possibly Limited/Adequate HL *n*= 32	*p*
cJADAS10, median (IQR)	8 (3.0–11.0)	2.2 (0.0–7.0)	0.017 *	4.2 (1.5–7.8) $n = 4$	0 (0.0- 2.0) $n = 27$	0.149
PROMIS composite, median (IQR)	40.5 (36.7–52.9) $n = 10$	38.7 (31.2–52.9) $n = 28$	0.654	35.3 (27.1–45.4) $n = 4$	52.1 (52.1–52.9) $n = 30$	0.037 *
Patient self-report 7a (secondary)	38.7 (36.7–52.9) $n = 9$	38.7 (29.5, 52.9) $n = 22$	0.695	38.7 (38.7–38.7) $n = 1$	52.9 (42.3–52.9) $n = 17$	0.247
Parent proxy 7a (secondary)	52.1 (52.1–52.1) $n = 1$	45.9 (36.5–52.1) $n = 6$	0.453	31.9 (22.4–52.1) $n = 3$	52.1 (52.1–52.1) $n = 13$	0.158
Steroid courses ** median (IQR)	3 (1.0–4.0) $n = 11$	1.5 (1.0–4.0) $n = 28$	0.522	2.5 (2.0–3.0) $n = 4$	2 (1.0–3.0) $n = 32$	0.546
Joint Count						
Initial	7 (5.0–8.0) $n = 9$	10 (5.0–10.0) $n = 25$	0.283	1 (1.0–1.5) $n = 4$	1 (1.0–3.0) $n = 32$	0.45
6 months	4 (1.0–7.0) $n = 6$	0 (0.0–4.0) $n = 23$	0.187	1 (0.5–1.5) $n = 4$	1 (0.0–1.0) $n = 31$	0.468
12 months	1 (0.0–2.0) $n = 5$	0 (0.0–0.0) $n = 21$	0.152	1 (0.0–2.5) $n = 4$	0 (0.0–1.0) $n = 26$	0.329
Disease activity at most recent visit ††	$n = 10$	$n = 28$	0.059	$n = 4$	$n = 27$	0.272
Inactive (cJADAS10 ≤ 1)	1/10 (10.0)	13/28 (46.4)		1/4 (25.0)	18/27 (66.7)	
Active (cJADAS10 > 1)	9/10 (90.0)	15/28 (53.6)		3/4 (75.0)	9/27 (33.3)	

Table 2. *Cont.*

(**b**)

Outcome	Limited HL *n*= 15	Possibly Limited Adequate HL *n*= 60	Effect Size (95% CI)	*p*
No-show rate, median (IQR)	6 (2–12) *n* = 15	1 (0–4) *n* = 59	+5 pp (0 to +9)	0.006 *
≥1 JIA-related ED visit	3/15 (20.0)	3/60 (5.0)	+15.0 pp (−6.0 to +36.0)	0.090
Medication nonadherence	6/15 (40.0)	15/60 (25.0)	+15.0 pp (−12.1 to +42.1)	0.335
Evidence of patient portal use	12/15 (80.0)	59/60 (98.3)	−18.3 pp (−38.8 to +2.2)	0.024 *

Limited HL: Newest Vital Sign (NVS) score 0–1. Possibly limited/adequate HL: NVS score 2–6. cJADAS10: clinical Juvenile Arthritis Disease Activity Score based on a ten-joint count; active disease defined as cJADAS10 > 1. PROMIS: Patient-Reported Outcomes Measurement Information System. The composite mobility measure is the pre-specified analysis and uses the Pediatric Mobility Short Form 7a for children aged 8 years and older and the Parent Proxy Mobility Short Form 7a for children younger than 8 years; the two component instruments are reported separately beneath it as secondary descriptive information. ** A steroid course is a discrete prescription of systemic glucocorticoid for JIA disease activity. †† Disease activity status was available for 69 out of 75 participants; denominators are given in the table. *p*-values are from the Wilcoxon rank-sum test for continuous variables and Fisher's exact test for categorical variables. Risk difference confidence intervals are Wald intervals for the difference of two independent proportions. *p*-values are from the Wilcoxon rank-sum test for the no-show rate and Fisher's exact test for the categorical outcomes. * $p < 0.05$.

Whole-cohort outcomes are shown in Table 2b. Patients in the limited HL group had significantly higher no-show rates than the possibly limited/adequate HL group [median 6 (IQR 2–12) vs. 1 (IQR 0–4); $p = 0.006$] and were less likely to have evidence of patient portal use [12 out of 15 (80.0%) vs. 59 out of 60 (98.3%); risk difference of 18.3 percentage points, 95% CI −38.8 to +2.2; $p = 0.024$]. There was no significant difference in JIA-related emergency department visits [3 out of 15 (20.0%) vs. 3 out of 60 (5.0%); risk difference +15.0 percentage points, 95% CI −6.0 to +36.0; $p = 0.090$] or in documented medication nonadherence [6 out of 15 (40.0%) vs. 15 out of 60 (25.0%); risk difference +15.0 percentage points, 95% CI −12.1 to +42.1; $p = 0.335$]. There was no difference in time to diagnosis. There was no significant difference in time from order to first administration of a csDMARD or a bDMARD between HL groups.

3.3. Characteristics and Outcomes by Survey Language

Table 3 summarizes demographics and outcomes by the survey language. There was a disproportionate number of polyarticular patients in the Spanish group (72.7% vs. 43.4%, $p = 0.025$) as well as a significantly higher percentage of patients with limited HL ($p < 0.001$). Similarly to possibly limited/adequate HL, English language was associated with living in the United States for more than 10 years ($p < 0.001$), more than a high school education ($p < 0.001$), significantly higher income ($p < 0.001$), and having private insurance ($p < 0.001$). When comparing region of heritage, Spanish speakers had a higher percentage of Central American ancestry when compared to English speakers (50% vs. 13.3%, $p = 0.023$). There was no difference in age of patient, time of clinical course, successful use of Medicaid transportation, household size, or housing situation between groups. Spanish speaking patients had significantly higher cJADAS10 scores [3.5 (IQR 0.5–10.2) vs. 1.0 (IQR 0.0–5.0); $p = 0.033$]. There was no difference in active vs. inactive disease, number of ED visits, patient portal use, documented medication nonadherence, mobility scores, no-show rate, number of steroid courses, or joint count at different time points between language groups.

Table 3. Demographic characteristics and outcomes by survey language.

Characteristic	*n* with Data	Spanish (*n* = 22)	English (*n* = 53)	*p*
JIA subtype	75	*n* = 22	*n* = 53	0.025 *
Oligoarticular		6 (27.3)	30 (56.6)	
Polyarticular		16 (72.7)	23 (43.4)	
Annual household income, USD, median (IQR)	Spanish =9 English = 34	33,600 (24,000–40.000)	137,500 (70,000–200,000)	<0.001 *
Health literacy (NVS score)	75	*n* = 22	*n* = 53	<0.001 *
0–1 (limited HL)		11 (50.0)	4 (7.5)	
2–3 (possible limited HL)		6 (27.3)	5 (9.4)	
4–6 (adequate HL)		5 (22.7)	44 (83.0)	
Time living in USA	74	*n* = 22	*n* = 52	<0.001 *
1–5 years		7 (31.8)	0 (0.0)	
6–10 years		2 (9.1)	1 (1.9)	
>10 years		13 (59.1)	51 (98.1)	
Region/heritage ‡	37	*n* = 22	*n* = 15	0.023 *
Mexico		7 (31.8)	4 (26.7)	
Central America		11 (50.0)	2 (13.3)	
South America		1 (4.5)	1 (6.7)	
Other		3 (13.6)	8 (53.3)	
Parental education	73	*n* = 21	*n* = 52	<0.001 *
Less than high school		8 (38.1)	0 (0.0)	
High school or GED		8 (38.1)	8 (15.4)	
More than high school		5 (23.8)	43 (82.7)	
Choose not to answer		0 (0.0)	1 (1.9)	
Work situation	73	*n* = 21	*n* = 52	0.017 *
Unemployed		5 (23.8)	6 (11.5)	
Part time		3 (14.3)	7 (13.5)	
Full time		7 (33.3)	35 (67.3)	
Otherwise unemployed but not seeking work		4 (19.0)	4 (7.7)	
Choose not to answer		2 (9.5)	0 (0.0)	
Insurance	73	*n* = 21	*n* = 52	<0.001 *
None		8 (38.1)	2 (3.8)	
Public non-Chip		10 (47.6)	13 (25.0)	
Public CHIP		2 (9.5)	0 (0.0)	
Private insurance		1 (4.8)	37 (71.2)	
cJADAS 10, median (IQR)	69	3.5 (0.5, 10.2) *n* = 20	1 (0.0, 5.0) *n* = 49	0.033 *
Disease activity at most recent visit	69	*n* = 20	*n* = 49	0.439
Inactive disease		8 (40.0)	25 (51.0)	
Active disease		12 (60.0)	24 (49.0)	
No-show rate, median (IQR)	74	4 (0.0, 10.0) *n* = 21	1 (0.0, 5.0) *n* = 53	0.088
Evidence of patient portal use (e.g., refill request)	75	*n* = 22	*n* = 53	0.073
No		3 (13.6)	1 (1.9)	
Yes		19 (86.4)	52 (98.1)	

Table 3. *Cont.*

Characteristic	*n* with Data	Spanish (*n* = 22)	English (*n* = 53)	*p*
Support system contact	73	*n* = 21	*n* = 52	<0.001 *
< once a week		6 (28.6)	1 (1.9)	
1 or 2 times a week		5 (23.8)	8 (15.4)	
3 to 5 times a week		2 (9.5)	9 (17.3)	
5 or > times a week		3 (14.3)	32 (61.5)	
Choose not to answer		5 (23.8)	2 (3.8)	

Values are *n* (%) unless otherwise stated. Percentages are calculated based on the number with non-missing data for each variable. NVS: Newest Vital Sign. cJADAS10: clinical Juvenile Arthritis Disease Activity Score based on a ten-joint count. ‡ See the footnote to Table 1. GED: General Educational Development; CHIP: Children's Health Insurance Program. * $p < 0.05$.

3.4. Predictors of Active Disease

Table 4 depicts the results of a multivariable logistic regression for active disease based on cJADAS10. The model was fitted to the 67 participants with complete outcome and covariate data, of whom 35 (52.2%) had active disease, corresponding to approximately 4.5 events per estimated parameter; the estimates are therefore imprecise and the model should be regarded as exploratory. After adjusting for insurance, survey language, documented medication nonadherence, and JIA subtype, limited HL was associated with higher odds of active disease, with a wide confidence interval (OR 6.96, 95% CI 1.19–40.81; $p = 0.031$). Documented medication nonadherence was also associated with higher odds of active disease (OR 6.39, 95% CI 1.78–22.94; $p = 0.004$). The confidence intervals for the remaining covariates are wide and, in the case of English language, span an order of magnitude in either direction; these estimates are not interpreted. The pre-specified interaction between HL group and JIA subtype was not statistically significant (likelihood-ratio test $p = 0.823$). The pre-specified interaction between HL group and survey language was non-estimable because of complete separation: all [four] children of English-speaking parents with limited HL had active disease.

Table 4. Multivariable logistic regression for active disease (cJADAS10 > 1).

Predictor (Reference Category)	Adjusted OR (95% CI)	*p*-Value	VIF
Limited HL (ref: possibly limited/adequate HL)	6.96 (1.19–40.81)	0.031 *	1.5
Public non-CHIP insurance (ref: uninsured)	1.24 (0.13–11.70)	0.850	2.67
Public CHIP insurance (ref: uninsured)	0.61 (0.03–11.53)	0.739	1.15
Private insurance (ref: uninsured)	0.60 (0.05–7.17)	0.684	5.47
English survey language (ref: Spanish)	1.91 (0.32–11.54)	0.479	6.59
Documented medication nonadherence (ref: none documented)	6.39 (1.78–22.94)	0.004 *	1.46
Polyarticular subtype (ref: oligoarticular)	3.16 (0.99–10.04)	0.051	2.16

Model fitted through analysis of $n = 67$ participants, of whom 35 had active disease (approximately 4.5 events per estimated parameter); confidence intervals are correspondingly wide, and the model is exploratory. Two interaction terms were specified a priori and tested using a likelihood-ratio test: health literacy group × JIA subtype ($p = 0.823$) and health literacy group × survey language (no p value available because the model could not calculate one because all of the patients in the low HL group who were English speakers had high disease activity). Neither was significant and neither was retained. No other interaction terms were tested. VIF: variance inflation factors for the covariates in this model were [1.15–6.6]. OR: odds ratio; CI: confidence interval; CHIP: Children's Health Insurance Program. * $p < 0.05$.

4. Discussion

To our knowledge, this is the first study evaluating HL using a validated tool in parents of patients with JIA in a diverse population. In our study, 20% of parents had limited HL, which is similar to that reported by Dogan et al. [15] but higher than the study performed by Lazaroff et al. in which all parents had adequate HL [17]. Other studies that evaluate HL in patients with rheumatologic conditions report limited HL rates ranging from 7% to 42% [27–29]. Several factors may explain the prevalence of limited HL in our study population. Notably, the large proportion of immigrants may reflect limited familiarity with the U.S. healthcare system. Supporting this hypothesis, 12 out of 15 parents in the limited HL group (80.0%) reported Hispanic ethnicity and 5 out of 15 (33.3%) had resided in the United States for less than 10 years compared with 5 out of 59 (8.5%) of the remaining parents.

In our study, limited HL was associated with significantly higher disease activity in polyarticular patients and with an overall higher adjusted odds of active disease in an exploratory multivariable model with wide confidence intervals. Among oligoarticular patients, the difference in disease activity did not reach statistical significance. The median cJADAS10 and the proportion with active disease were both numerically higher in the limited HL group [3 out of 4 (75.0%) vs. 9 out of 27 (33.3%); risk difference +41.7 percentage points, 95% CI −4.3 to +87.7], but with only four oligoarticular patients in the limited HL group, this estimate is too imprecise to interpret. We draw no assumptions from the direction of the oligoarticular findings. Whether the association differs by subtype cannot be determined from these data; the formal test of interaction between HL group and subtype was not significant but was itself underpowered. Additionally, oligoarticular patients in the limited HL group had lower composite PROMIS mobility scores, again based on four patients. Thus, in this cross-sectional cohort, limited parental HL was associated with less favorable clinical outcomes. Because exposure and outcome were measured at the same time point, the direction of any relationship cannot be established from these data.

These findings must be interpreted in light of the structure of our cohort. Limited parental HL did not occur in isolation; it co-occurred with Spanish language, Hispanic ethnicity, lower educational attainment, lower household income, and absence of insurance. HL may therefore be acting partly or wholly as a marker of these broader socioeconomic and access-related circumstances rather than as an independent determinant of disease activity. The wide confidence intervals for insurance and survey language also reflect their collinearity in this cohort (variance inflation factors up to 6.6), which further limits interpretation of the individual covariate estimates. We do not interpret that estimate, and we do not claim to have isolated an independent effect of HL. What our data support is that limited parental HL identifies a group of children with substantially higher disease activity, which is clinically useful whether HL is a cause, a marker, or both, while leaving the mechanism unresolved. Reverse causation also cannot be excluded, as the demands of managing more active disease may themselves shape a parent's HL score at a single assessment.

Although no association was seen between parental HL and JIA outcomes in the study performed by Dogan et al. [15] and Lazaroff et al. [17], these represented homogeneous populations with similarities in language and acculturation. Studies that have evaluated the role of HL in outcomes of rheumatologic conditions in diverse populations have also identified an association between HL and outcomes [28,30]. A systematic review of forty-nine studies evaluated the role of HL and outcomes of children with chronic disease, including one study in patients with JIA, found that in both high-income countries and low-income countries, limited parental HL was associated with poorer child health outcomes [30]. Higher HL in patients with childhood lupus has been associated with higher medication adherence and higher quality of life [28]. A study that evaluated disease activity over time in 108 patients

with rheumatoid arthritis found that patients with adequate HL had significantly lower disease activity over time than patients with more severe HL limitations [31].

In our cohort, the no-show rate was significantly higher in the limited HL group. Because no-show rates did not differ significantly by language, HL may contribute to missed appointments independently of language; however, the language comparison was itself non-significant rather than null, and the two exposures are strongly correlated in this cohort, so this interpretation is tentative. Transportation-related barriers did not differ significantly between the limited HL group and the possibly limited/adequate HL group, although with only three participants reporting transportation difficulties this comparison has very little power and does not exclude a contribution. We hypothesize that other factors may contribute, including confusion about appointment dates and times, limited access to patient portals and automated appointment reminders, inadequate understanding of the importance of regular follow-up visits, or difficulties obtaining time off of work to attend appointments. These mechanisms were not measured in this study and are offered as hypotheses for future work. Patient portal use was also significantly lower in the limited HL group. A systematic review evaluating the effect of patient portals on health outcomes demonstrated improved monitoring of health status, physician–patient interactions, and quality of care [32]. Sun et al. examined the impact of several socioeconomic factors on patient portal utilization and found that individuals who identified as Black or African American, spoke Spanish as their primary language, were male, reside in rural areas, or lack health insurance had significantly lower odds of using patient portal [33].

Our cohort highlights the presence of multiple social, demographic, and environmental disparities that may influence HL. Parents with higher HL and English as their primary language have significantly higher income, education, and private insurance and are less likely to report specific needs such as food, clothing, utilities, childcare, healthcare, and phone. These differences stress the importance of getting social work involved for families whose parents are Spanish speakers and who have limited HL to help address some of these barriers. One key difference between HL groups was contact with a support system, with parents with limited HL having significantly less social support. This finding may relate to duration of residence in the United States among families with limited HL, although we did not measure social support longitudinally and cannot establish its origin. We also note that a substantial and differential proportion of the limited HL group declined to answer the PRAPARE needs inventory, so the burden of unmet social need in that group is likely to be understated; differential non-response is itself a finding that warrants attention in the design of future studies in this population.

There was no significant difference in time to csDMARD or bDMARD therapy initiation between limited and possibly limited/adequate HL groups. Access to medications may be related to Medicaid insurance coverage, specialty pharmacy services, and patient assistance programs. A key program in our institution is the specialty pharmacy, which delivers medications to patients' homes, a strategy that may be filling gaps in HL. It is worth noting, however, that both specialty pharmacies and patient assistance programs require significant interactions with the healthcare system such as providing proof of income and coordinating deliveries. Our institution helps overcome some of these barriers by having a high percentage of Spanish speaking staff (nurses, PA specialists, and physicians).

Research examining targeted health literacy interventions has shown improvements in health knowledge, health-related behaviors, and healthcare utilization [34,35]. In a 2022 study of 13 young adult patients with systemic lupus who had successfully transitioned into adult care, patients expressed frustration and hesitance with doctors' explanations regarding the disease process and the rationale behind treatments [36]. The authors further noted physician's explanations frequently relied on "doctor talk", which may hinder patient

understanding, and recommended cultural competency training to enhance physician–patient communication. Topics that patients expressed that they personally had difficulty with included how to identify doctors through insurance, difficulty getting appointments, knowing how to ask for refills, and knowing their own personal medical history when asked at the adult visit. A systemic review of 24 randomized controlled trials evaluating the efficacy of educational interventions in adults with rheumatoid arthritis found significant effects on physical function, disease activity, arthritis self-efficacy, and general health [35]. Studies evaluating the impact of educational interventions in JIA specifically are limited, and whether similar interventions would produce comparable benefits in JIA has not been established.

Limitations of our study include a small sample size. The cross-sectional design means that exposure and outcome were ascertained simultaneously, so neither temporal precedence nor causation can be established, and reverse causation cannot be excluded. Because limited HL co-varied closely with language, ethnicity, education, income, and insurance in this cohort, residual socioeconomic confounding cannot be excluded, and we cannot claim to have isolated an independent effect of HL. Our a priori sample size estimate anchored the target difference to published cJADAS10 disease activity state cut-offs rather than an empirically observed between-group difference, and the achieved distribution of participants across HL groups within JIA subtypes was more unbalanced than anticipated; the subgroup analyses are consequently underpowered and are presented as exploratory. The multivariable model was fitted and exploratory with approximately 4.5 events per estimated parameter, well below conventional recommendations, and several confidence intervals are correspondingly wide. Excluding extended oligoarticular, systemic, psoriatic, and enthesitis-related subtypes improved the interpretability of subtype comparisons but limits generalizability to the full JIA population. Restriction to English- and Spanish-speaking families excludes those facing the greatest language barriers, who may plausibly have the lowest HL. Two chart-abstracted variables required clinical judgment, and the abstractor was not blinded to HL group. We think it likely that HL rates are underestimated given that patients with limited HL may have difficulty making it to appointments. Higher HL has been associated with higher research participation, and limited HL has been linked with lower completion of research visits [37,38]. Other limitations include the incomplete response rate in some of the questions, including 13.3% of parents choosing not to answer the PRAPARE item that asked if there were any needs. Factors contributing to incomplete responses included reluctance to disclose financial information and apprehension regarding the potential impact of survey responses on custody cases, even though families were assured of the confidentiality of their responses. Specific data on which csDMARD or bDMARD was used in each patient was not obtained, which is also a limitation. Finally, this was a single-center study at an institution with a high proportion of Spanish-speaking clinical staff and an established specialty pharmacy, both of which may attenuate the effects of limited HL and limit generalizability to settings without these resources.

In conclusion, in this single-center cross-sectional cohort, limited parental HL was associated with higher disease activity in children with polyarticular JIA and higher adjusted odds of active disease in an exploratory adjusted analysis. Limited parental HL was also associated with a higher no-show rate, lower patient portal use, and less frequent contact with a support system. Because HL in this cohort was closely bound up with language, education, income, and insurance, and because exposure and outcome were assessed at the same time point, these findings identify an association rather than a causal pathway.

These observations suggest, but do not establish, several directions for intervention. Routine screening of parental HL in JIA clinics would identify families in whom additional support might be warranted, but neither the feasibility nor the yield of such screening

was evaluated here. Interventions targeting the specific gaps we observed, including, for example, a short instructional video on activating and troubleshooting the patient portal and completing patient assistance applications for JIA therapies or proactive social work referral for families with limited HL are all plausible, but their effectiveness in JIA is untested. Prospective studies, ideally using large multicenter cohorts to separate HL from correlated socioeconomic factors and establish temporal relationships, are needed before such measures could be recommended.

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