

# Parental Health Literacy and Outcomes of Childhood Nephrotic Syndrome

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abstract

**OBJECTIVE:** Determine the association of parental health literacy with treatment response among children with nephrotic syndrome.

**METHODS:** This was a cohort study of children aged 1–18 with nephrotic syndrome and their parent. Health literacy was measured using the validated Short Test of Functional Health Literacy in Adults assessing reading comprehension and numeracy. Outcomes included initial relapse-free period, frequently relapsing disease, relapse rate, second-line medication use, and complete remission after therapy.

**RESULTS:** Of 190 parents, 80% had adequate health literacy (score >67 of 100), and higher scores were not correlated with higher education. Almost all achieved perfect numeracy scores (>86%); numeracy was not associated with outcomes. After adjusting for immigration, education, and income, higher reading comprehension scores (tertile 3) compared with lower scores (tertile 1) were significantly associated with lower risk of first relapse (hazard ratio 0.67, 95% confidence interval [CI] 0.48–0.94, *P* trend = .02), lower odds of frequently relapsing disease (odds ratio [OR] 0.38, 95% CI 0.21–0.70, *P* trend = .002), lower relapse rate (rate ratio 0.77, 95% CI 0.73–0.80, *P* trend < .001), and higher odds of complete remission after both initial steroids and cyclophosphamide (OR 2.07, 95% CI 1.36–3.16, *P* trend = .003; OR 5.97, 95% CI 2.42–14.7, *P* trend < .001).

**CONCLUSIONS:** Lower parental health literacy, specifically reading comprehension, is associated with higher relapse rates among children with nephrotic syndrome and fewer achieving complete remission. This underscores the importance of assessing and targeting health literacy for chronic management of childhood-onset diseases.

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**WHAT'S KNOWN ON THIS SUBJECT:** Low health literacy is associated with poor outcomes in chronic diseases. The association between parental health literacy and longitudinal outcomes in a pediatric chronic disease has not been studied.

**WHAT THIS STUDY ADDS:** We demonstrate that poor parental health literacy is associated with more relapses among children with nephrotic syndrome and fewer achieving complete remission. Health professionals should seek to identify parents who may benefit from more focused teaching.

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Health literacy is the ability of individuals to access, understand, and use health information to make appropriate decisions about their health care.<sup>1,2</sup> Basic health literacy encompasses reading comprehension and numeracy skills, which are important to read, process, and understand instructions as well as manage the mathematical demands of any situation.<sup>1,3</sup> Both skills are essential to interpret and apply information received for the prevention or self-management of disease and promotion of one's health. Health literacy also includes several other skills including writing, speaking, listening, and the ability to advocate for oneself in the health care system.<sup>4</sup> The lack of health literacy poses a significant challenge in the health care setting as deficits are noted in up to 60% of people in North America.<sup>1,2</sup>

Young children are largely dependent on parents to manage and advocate for their health care needs. Low health literacy among parents has been associated with poor health knowledge,<sup>5-8</sup> potentially detrimental health behaviors,<sup>9-11</sup> and inability to accurately understand or follow health care directives for their child as well as low adherence to treatment regimens.<sup>12-17</sup> The limited data linking low parental health literacy to child health outcomes in chronic diseases concentrates primarily on health care utilization and regulation of diabetes and asthma.<sup>18,19</sup> A recent trial among pediatric providers uses a written communication tool that focuses on low literacy to improve quality of counseling and suggests that methods of clearer communication may improve outcomes.<sup>20</sup> In many pediatric chronic diseases, there is variability in outcomes, often attributed to drug adherence or differences in pathogenesis, but no studies have investigated parental health literacy with longitudinal

outcomes specifically in childhood-related kidney diseases.

Nephrotic syndrome is the most commonly acquired kidney disease in children and is characterized by a relapsing and remitting disease course treated with steroids at disease onset and at each relapse. Frequent relapses are common and require a high degree of parental home-based management with regular monitoring of urine dipsticks, administering medication regimens with tapering doses and alternate day schedules, and seeking medical attention for relapses or lack of response to steroids in a timely manner. Comorbidities such as infection, thrombosis, and acute kidney injury are not uncommon with each relapse, and therefore close parental monitoring is vital. There is also significant individual variability in the frequency of relapses and treatment response in childhood nephrotic syndrome that may be explained in part by health literacy. Thus, we sought to examine the association of parental health literacy and long-term outcomes of children with nephrotic syndrome. Understanding the impact of parental health literacy will help tailor interventional teaching efforts to families to improve outcomes.

## METHODS

### Study Design, Population, and Data Collection

The Insight into Nephrotic Syndrome: Investigating Genes, Health and Therapeutics (INSIGHT) study is a disease-based observational cohort study based in the Greater Toronto Area.<sup>21</sup> It includes children diagnosed with nephrotic syndrome between 1 and 18 years old, excluding those with congenital nephrotic syndrome, disease with multiple organs involved, or conditions such as systemic lupus erythematosus or vasculitis. The study was approved by the Hospital for Sick Children's

Research Ethics Board (ClinicalTrials.gov identifier NCT01605266). Informed consent was obtained by parents/guardians and participants with the capacity to consent or assent.

Demographic and health literacy data were collected from questionnaires completed by 1 parent of each family participating in the INSIGHT study at the time of their enrollment. A total of 216 parents completed the baseline questionnaire. Of those parents, 26 were unable to complete the health literacy assessment (6 refused or were discharged from clinic before the health literacy test could be completed, and 20 were unable to complete the health literacy test due to a language barrier) for final cohort of 190 participants. Clinical data were collected from electronic patient charts from time of diagnosis until transfer to adult care/another hospital ( $n = 4$ ), discharge from clinic without active disease ( $n = 23$ ), or until the last follow-up date of May 21, 2014.

## Education

Since 1993, there has been a nurse-managed outpatient program at The Hospital for Sick Children to teach self-monitoring for nephrotic syndrome for families with newly diagnosed children. Monitoring at home is important to promptly identify a relapse or resistant disease and report to clinic. Teaching by nurses is standardized and includes an explanation of the disease, use of medications, and how to measure daily urine protein. It also explains the situations in which the family would need to contact the nurses. Children enrolled in INSIGHT but seen at a community hospital may not have had access to this family-centered program and were provided teaching from their community nephrologist affiliated with Hospital for Sick children using similar clinical protocols.

## Health Literacy Measurement

The Short Test of Functional Health Literacy in Adults (S-TOFHLA)<sup>22</sup> is a validated measure of health literacy that assesses numeracy and reading comprehension. Categorization of scores is typically defined as inadequate (score 0–35), marginal (score 36–53), and adequate health literacy (score 54–66).<sup>22</sup> Only the English-language version of S-TOFHLA was used for this study. All parents enrolled were asked if they were fluent or confident enough in English (both speaking and reading) to take a test in English. Those who identified English as a language barrier did not complete the S-TOFHLA.

In this parent population, the majority had overall scores of  $\geq 67$  and were deemed to have adequate health literacy; thus, we assessed rank order for reading comprehension and overall scores using tertiles (low, medium, high) for analyses. Numeracy scores were dichotomized into perfect scores (score of 28) and less than perfect ( $< 28$ ). Those unable to take the S-TOFHLA were analyzed separately.

## Covariates

Age, ethnicity, immigration status, level of school completed, and annual household income of parents were obtained by self-report through questionnaires. Annual household income was dichotomized using the low income cutoff of  $\sim \$35\,000$  as defined by Statistics Canada.<sup>23</sup> Sex, age at diagnosis, and immigration status of the child were also obtained through questionnaires.

## Outcomes

All children were treated with prednisone at presentation using a 16-week standardized clinical protocol involving  $60\text{ mg/m}^2$  per day for 6 weeks followed by an alternate day taper for 10 weeks. Relapse was defined as  $> 3.0\text{ g/L}$  of protein on urine dipstick for at least 3

consecutive days resulting in the use of steroids or an increase in steroid dose. Relapse rate was defined as number of relapses per year within the time followed up to 2 years. Initial steroid resistance was defined as not achieving remission within the initial treatment period and requiring a second-line medication. Frequently relapsing nephrotic syndrome was defined as having  $\geq 2$  relapses in the first 6 months after diagnosis or  $\geq 4$  relapses in the first year after diagnosis. Use of a second-line medication was defined as the prescription of a steroid-sparing medication for the treatment of nephrotic syndrome. Complete remission was defined as no further relapses after the initial steroid course or after cyclophosphamide.

## Statistical Analyses

Characteristics were described using means (SD) for normally distributed data and medians (interquartile range [IQR]) for nonnormally distributed data. Characteristics were compared across overall health literacy tertiles using  $\chi^2$ , *t* tests, Fisher's exact, or rank-sum tests, as appropriate. A Cox proportional hazards model was used to evaluate the association of reading comprehension score, numeracy score, and overall score with the risk of first relapse and second-line medication use. A negative binomial regression was used to examine the association of health literacy score with relapse rate (presented as a rate ratio). Logistic regression was used to examine association of health literacy score with odds of frequently relapsing disease and complete remission.

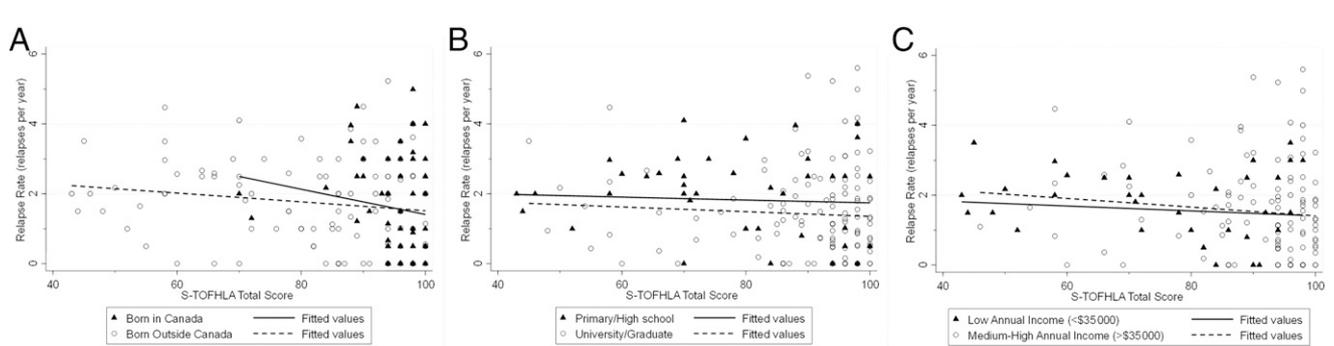
Reading comprehension score and overall score analyses evaluated the higher scoring tertiles in comparison with the lowest scoring tertile as well as the overall trend across tertiles. Numeracy score was compared dichotomously as perfect compared with not-perfect

scores. Initial steroid resistant cases ( $n = 10$ ) were excluded from outcome analyses. Models were clustered by clinic center to account for differences in education and treatment among clinic centers and were adjusted for parent sex, immigration status, education level, and family income. Ethnicity was not included in adjustment due to high correlation with immigration status. All statistical analysis was performed using Stata/SE 14 (StataCorp, College Station, TX), and  $P < .05$  was considered significant.

## RESULTS

Table 1 describes the demographic and clinical characteristics of the 190 parents (1 per family) of 190 children included in the analysis. The majority of children were male (65%) with a median age at diagnosis of 3.5 years (IQR 2.6–5.5). The mean age of parents was  $39.1 \pm 6.6$  years at time of assessment, and the majority (71%) were mothers. Overall, the majority of Europeans scored in the medium and high scoring tertiles, and the majority of South Asians scored in the medium and low scoring tertiles. More than 76% of parents reported postsecondary education level or higher. Sixty-two percent of parents were born outside Canada, and 21% had a low family income, with the highest proportions among the low scoring group. Characteristics of the children were similar in age, sex, immigration status, and outcomes among the 3 tertiles of overall health literacy score.

Children were followed for a median of 2.7 years (IQR 1.3–4.6). Approximately 16% of children had frequently relapsing disease at 12 months after diagnosis and the median relapse rate was 1.3 relapses per year (IQR 0.4–2.3). More than 21% of children had no further relapses after initial therapy, and of the 80 children who went on to use cyclophosphamide as a second-line



**FIGURE 1**

Scatterplot of S-TOFHLA overall health literacy score and relapse rate by (A) immigration status, (B) educational status, and (C) income status.

treatment, 38% had no further relapses. Figure 1 shows the inverse correlation of S-TOFHLA overall health literacy score with relapse rate by immigration status, education level, and income status. The line of best fit was steeper among those born outside of Canada than those born in Canada.

In analyses examining the association of health literacy score and clinical outcomes of nephrotic syndrome, reading comprehension score was significantly associated with all outcomes analyzed (Table 2). Specifically, higher reading comprehension scores were significantly associated with

decreased risk of first relapse after adjusting for parent sex, immigration status, education, and income, with a 33% lower risk of relapse among those in the highest tertile compared with the lowest tertile (tertile 3 vs 1 hazard ratio 0.67, 95% confidence interval [CI]: 0.48–0.94,  $P$  trend = .02).

**TABLE 1** Baseline Characteristics of 190 Children With Nephrotic Syndrome and Their Parent ( $N = 190$ )

	Tertile 1	Tertile 2	Tertile 3	Total ( $N = 190$ )
Overall health literacy score, range	(43–86)	(87–96)	(97–100)	—
Sample size	( $n = 64$ )	( $n = 76$ )	( $n = 50$ )	—
Parent characteristics				
Male ( $n = 184$ ), $n$ (%)	24 (39.3)	18 (24.0)	10 (20.8)	52 (28.3)
Age at study visit (y)	39.6 ± 6.7	38.6 ± 6.9	39.5 ± 6.1	39.1 ± 6.6
Self-reported ethnicity ( $n = 185$ ), $n$ (%)				
European	4 (6.5)	31 (41.3)**	28 (58.4)**	63 (34.0)
South Asian	43 (69.3)	23 (30.7)**	5 (10.4)**	71 (38.4)
East/Southeast Asian	7 (11.3)	10 (13.3)	4 (8.3)	21 (11.4)
Other <sup>a</sup>	8 (12.9)	11 (14.7)	11 (22.9)	30 (16.2)
Education level ( $n = 186$ ), $n$ (%)				
Primary/secondary	27 (43.5)	12 (16.0)**	5 (10.2)**	44 (23.7)
Postsecondary	35 (56.5)	63 (84.0)**	44 (89.8)**	142 (76.3)
Annual family income below LIC0 <sup>b</sup> ( $n = 164$ )	22 (40.7)	12 (18.2)*	1 (2.3)**	35 (21.3)
Born in Canada ( $n = 183$ )	4 (6.6)	36 (48.0)**	29 (61.7)**	69 (37.7)
Single-parent family ( $n = 185$ )	7 (11.3)	9 (12.2)	6 (12.2)	22 (11.9)
Child characteristics				
Male, $n$ (%)	43 (67.2)	49 (64.5)	31 (62.0)	123 (64.7)
Age at diagnosis (y), $n$ (IQR)	3.4 (2.8–5.2)	3.7 (2.4–5.6)	3.4 (2.6–5.9)	3.5 (2.6–5.5)
Born in Canada ( $n = 186$ ), $n$ (%)	56 (90.3)	65 (86.7)	44 (89.8)	165 (88.7)
Clinical outcomes				
Initial steroid resistance, $n$ (%)	2 (3.1)	6 (7.9)	2 (4.0)	10 (5.3)
FRNS at 12 mo, $n$ (%)	10 (15.6)	13 (17.1)	8 (16.0)	31 (16.3)
Relapse rate (per y), $n$ (IQR)	1.50 (0.73–2.34)	1.20 (0.42–2.33)	1.00 (0–1.88)	1.30 (0.44–2.27)
Use of second-line medication, $n$ (%)	34 (53.1)	42 (55.3)	23 (46.0)	99 (52.1)
CR after initial therapy, $n$ (%)	11 (17.2)	16 (21.0)	13 (26.0)	40 (21.1)
CR after cyclophosphamide ( $n = 80$ ), $n$ (%)	9 (31.0)	13 (37.1)	8 (50.0)	30 (37.5)
Median d to cyclophosphamide ( $n = 80$ ), $n$ (IQR)	255 (180–488)	290 (98–486)	236 (157–504)	269 (152–487)

CR, complete remission; FRNS, frequently relapsing nephrotic syndrome; LIC0, low-income cutoff. Statistical tests conducted using tertile 1 as reference group. Variables with incomplete information for all 190 parents have population stated in parentheses.

<sup>a</sup> Other includes Middle Eastern, West Indian/Caribbean, African, Mexican or South or Central American, Aboriginal, and Multiethnic.

<sup>b</sup> Income <\$35 000 as defined by Statistics Canada.

\*  $P < .05$  using  $\chi^2$ ,  $t$  test, or Fisher's exact test.

\*\*  $P < .001$  using  $\chi^2$ ,  $t$  test, or Fisher's exact test.

**TABLE 2** Association of Parental Health Literacy With Clinical Outcomes Among Children With Nephrotic Syndrome

Tertile Scores	Overall Health Literacy Score			Reading Comprehension Score			Numeracy Score		
	Tertile 1 43-86 (n = 62)	Tertile 2 87-96 (n = 70)	Tertile 3 98-100 (n = 48)	Tertile 1 18-62 (n = 72)	Tertile 2 64-68 (n = 56)	Tertile 3 70-72 (n = 52)	Trend P	<28 (n = 26)	28 (n = 154)
Sample size									
First relapse									
HR	ref	0.86	0.86*	ref	0.68*	0.76**	<.001	ref	1.04
95% CI	—	0.63-1.18	0.77-0.96	—	0.53-0.87	0.71-0.80		—	0.88-1.23
aHR	ref	0.84	0.82	ref	0.66	0.67*	.020	ref	1.04
95% CI	—	0.47-1.53	0.62-1.07	—	0.36-1.19	0.48-0.94		—	0.86-1.27
Frequently relapsing disease <sup>a</sup>									
OR	ref	1.19	1.04	ref	0.63*	0.69*	.007	ref	1.17
95% CI	—	0.56-2.52	0.70-1.55	—	0.46-0.86	0.53-0.89		—	0.83-1.64
aOR	ref	0.97	0.70*	ref	0.43**	0.38*	.002	ref	0.82
95% CI	—	0.55-1.72	0.50-0.97	—	0.28-0.68	0.21-0.70		—	0.65-1.03
Relapse rate <sup>b</sup>									
RR	ref	1.04	0.99	ref	0.81**	0.87**	<.001	ref	0.99
95% CI	—	0.83-1.30	0.92-1.07	—	0.74-0.90	0.81-0.93		—	0.77-1.27
aRR	ref	1.07	0.96	ref	0.78**	0.77**	<.001	ref	0.91
95% CI	—	0.80-1.41	0.90-1.01	—	0.68-0.90	0.73-0.80		—	0.71-1.16
Use of second-line medication									
HR	ref	1.05	0.87	ref	0.71**	0.76	.3	ref	0.90
95% CI	—	0.97-1.14	0.45-1.69	—	0.65-0.77	0.42-1.37		—	0.75-1.07
aHR	ref	1.36	1.12	ref	0.86	0.87	.3	ref	1.00
95% CI	—	0.83-2.24	0.82-1.55	—	0.54-1.37	0.64-1.20		—	0.87-1.15
CR after initial therapy									
OR	ref	1.37	1.72*	ref	1.51	2.03**	<.001	ref	0.94
95% CI	—	0.99-1.90	1.15-2.59	—	0.73-3.14	1.60-2.57		—	0.62-1.44
aOR	ref	1.40	1.68	ref	1.57	2.07*	.003	ref	1.13
95% CI	—	0.48-4.13	0.38-7.40	—	0.99-2.49	1.36-3.16		—	0.45-2.81
CR after cyclophosphamide									
OR	ref	1.19	2.19**	ref	2.34**	3.00**	<.001	ref	1.65
95% CI	—	0.80-1.78	1.47-3.26	—	1.55-3.52	1.64-5.49		—	0.62-4.36
aOR	ref	2.31*	2.66**	ref	6.47**	5.97**	<.001	ref	0.81
95% CI	—	1.11-4.79	1.94-3.65	—	4.96-8.44	2.42-14.7		—	0.41-1.62

aHR, adjusted hazard ratio; aOR, adjusted OR; aRR, adjusted rate ratio; CR, complete remission; HR, hazard ratio; RR, rate ratio. Model is adjusted for parent sex, immigration status, family income, and education level.

<sup>a</sup> Frequently relapsing at 1 y after diagnosis.

<sup>b</sup> Within first 2 y after diagnosis.

\*  $P < .05$ .

\*\*  $P < .001$ .

Higher reading comprehension score was also significantly associated with lower odds of frequently relapsing disease and lower rate of relapses within 2 years of diagnosis after multivariable adjustment, with a graded response across the tertiles (tertile 2 vs 1 odds ratio [OR] 0.43, 95% CI 0.28–0.68; tertile 3 vs 1 OR 0.38, 95% CI 0.21–0.70; *P* trend = .002 and tertile 2 vs 1 rate ratio 0.78, 95% CI 0.68–0.90; tertile 3 vs 1 rate ratio 0.77, 95% CI 0.73–0.80; *P* trend <.001). Higher reading comprehension scores were significantly associated with lower risk of second-line medication use; however, the association did not remain significant after adjustment.

For complete remission outcomes, reading comprehension scores were significantly associated with increased odds of complete remission after the initial course of steroids after multivariable adjustment (tertile 3 vs 1 OR 2.07, 95% CI 1.36–3.16; *P* trend = .003). Both higher reading comprehension and overall scores also showed significant association with increased odds of complete remission after cyclophosphamide treatment (~5 times higher in the highest reading comprehension group) after adjustment.

In stratified analysis, lower reading comprehension remained associated with higher risk of initial relapse regardless of whether children were seen through the nurse-managed program at SickKids or at other centers in the community without access to this program; however, the associations were not statistically significant likely because of the smaller sample sizes (data not shown).

## DISCUSSION

Parental health literacy is important in the management of young children with chronic disease, especially in those that require frequent

home monitoring. Among children with nephrotic syndrome, we demonstrate that lower parental health literacy, specifically lower reading comprehension, is associated with shorter relapse-free period after diagnosis, higher odds of frequently relapsing disease, higher rates of relapse, and lower odds of achieving complete remission independent of immigration status, education, and family income. This is critical because improving education about home management for families may directly benefit outcomes of children with chronic disease.

Lower reading comprehension was found to be significantly associated with higher risk of relapses, which requires repeated courses of steroids. The ability to read and understand written medication instructions such as tapering and/or alternating day schedules and then follow the instructions is a fundamental component of health literacy. Parents may be able to read the instructions but are not able to execute those instructions or understand the implications of not following the prescribed management, especially at the onset of their child's therapy. It is known that the first course of steroids is important in management of nephrotic syndrome because first responses guide future treatment decisions. Our data suggest that complete remission rates could be even higher if we are able to improve education about the disease with both the first course of steroids and also with the use of the second line agent, cyclophosphamide. Cyclophosphamide is administered daily for 3 months often with regular complete blood counts with possible dose adjustments if neutropenia detected, in addition to tapering steroids. Parents who are more health literate may be better able to manage administration of both medications and may seek medical attention earlier when the child is exposed to potential triggers for

relapse such as infection. Contrary to previous reports, no association was found between numeracy scores and disease outcomes.<sup>24</sup> This may be attributable to the little variability in numeracy scores among parents in our study.

Eighty percent of parents were deemed adequately health literate; however, rank order by tertiles was able to discern differences within the narrow range of the reading comprehension scores that were independent of immigration status, education, and income. Interestingly, higher education beyond high school did not correlate with higher health literacy, and also more than half of those with low health literacy reported postsecondary education or higher. This suggests that relying on education level alone as a surrogate measure of health literacy may prevent health care professionals from identifying families that might benefit from additional teaching and intervention. It may be important to consider health literacy screening regardless of highest attained education. In our study, however, we did not ask the country or language in which parents received their education, which may also be why high education level was not consistent with higher health literacy. Rather than assessing education level, clinical tools are needed to assess comprehension of home monitoring as well as facilitate daily tracking of medications, morning urinalysis, and reminders to call for specific findings.

For those identified as having low health literacy, it is important to further identify the mechanisms affecting health outcomes. Parents may lack understanding of how to manage their child's health and thus education may be one area to target. Take-home educational materials such as brochures and pamphlets that use pictures and simple wording can be an important strategy in facilitating health care.<sup>25</sup> The use

of illustrations and contextualized examples when explaining health information, standardized educational programs for health care professionals in written and verbal communication with individuals of lower literacy, and interactive information technology tools have also been proposed to tailor counseling in clinical settings.<sup>16,26,27</sup> Parents with low health literacy may also have other factors besides education affecting health outcomes such as less motivation to reach out to health professionals when having difficulties or needing more help negotiating through the health systems. In these cases, providing a better system of support and communication with nurses, physicians, and the rest of the health care team could help improve care. Web-based or cell phone applications may be a useful option for providing general disease information for parents while also providing support and communication with health care professionals and other parents dealing with disease. Further investigation of the mechanisms through which health literacy affects outcomes is crucial as the incorporation of health literacy assessment into clinical practice becomes more routine in ambulatory care.

This study has several strengths. The study population is a well characterized and ethnically diverse cohort that is larger than other previous pediatric chronic disease studies using S-TOFHLA and also assesses longitudinal outcomes.<sup>14,15</sup> Moreover, this study includes children from 2 centers that serve a

large region of the Greater Toronto Area and manage not only those with severe disease but a wide range of nephrotic cases. This study was conducted in a region with publicly funded health care, which minimizes the bias from access to health care. This is also the first study to our knowledge that addresses parental health literacy in the context of childhood nephrotic syndrome, a disease requiring a high degree of parental involvement and self-management analogous to asthma. The study has some limitations. We did not assess health literacy for both parents because this would have been difficult to obtain for many families that have only 1 parent attend clinic visits. Thus, the parent that completed the health literacy assessment may not be the sole caregiver, but in general most were filled out by the primary caregiver who comes to clinic appointments. We also cannot discount the contribution adolescents or older children may make to their own care; however, given that the majority of the children are between ages 2 and 6 years, it is reasonable to consider the parent the primary person making adjustments in medications and checking urine dipsticks. Finally, the S-TOFHLA assesses only reading and numeracy skills and cannot evaluate other important domains of health literacy. However, it is important to highlight that assessing just 2 of the most basic health literacy skills identified a difference in outcomes. Further studies are needed to investigate how a more comprehensive assessment of parental health literacy will affect child health outcomes.

## CONCLUSIONS

Poor health literacy among an ethnically diverse parent group is independently associated with a shorter time to first relapse, frequently relapsing disease, and lower odds of achieving complete remission. This association between lower parental health literacy and worse clinical outcomes highlights the role of parents in the chronic disease management of children with nephrotic syndrome and identifies a possible target for intervention. Future research is needed to study the impact of tailored educational interventions.

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## ABBREVIATIONS

CI: confidence interval  
INSIGHT, Insight Into Nephrotic Syndrome: Investigating Genes, Health and Therapeutics  
IQR: interquartile range  
OR: odds ratio  
S-TOFHLA: Short Test of Functional Health Literacy in Adults

This trial has been registered at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) (identifier NCT01605266).

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