Received: 1 October 2019 | Revised: 28 February 2020 | Accepted: 2 April 2020

DOI: 10.1111/petr.13726

ORIGINAL ARTICLE

WILEY

Health literacy and its association with adherence in pediatric liver transplant recipients and their parents

Dawn Dore-Stites[1] | M. James Lopez[1] | John C. Magee[3] | John Bucuvalas[4] | Kathleen Campbell[5] | Victoria Shieck[2] | Andrew Well[6] | Emily M. Fredericks[1]

[1]Department of Pediatrics and Communicable Diseases, University of Michigan, Ann Arbor, MI, USA

[2]Department of Transplant Center, University of Michigan, Ann Arbor, MI, USA

[3]Department of Surgery, University of Michigan, Ann Arbor, MI, USA

[4]Mount Sinai Beth Kravis Children's Hospital and the Recanati-Miller Transplant Institute, New York, NY, USA

[5]Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA

[6]Dell Medical School, University of Texas, Austin, TX, USA

Correspondence
Dawn Dore-Stites, Department of Pediatrics and Communicable Diseases, University of Michigan, F7801 UH South SPC 5203, 1500 E. Medical Center Drive, Ann Arbor, MI 48109-5203.
Email: dawndore@med.umich.edu

Abstract

Objective: Non-adherence to pediatric regimens is a common concern. Low health literacy is correlated with poor outcomes in adults but is understudied in pediatrics. The current project aimed to determine the relationship between health literacy, adherence, and outcomes in pediatric liver transplant recipients. Hypotheses included a) parent and patient health literacy would be positively correlated; and b) low patient and/or parent health literacy would be negatively correlated with adherence and health outcomes.

Patients and Methods: Eligible participants were recruited during routine follow-up visits in a pediatric liver transplant clinic. Parents and patients (>13 years old) completed 2 measures of health literacy. Patients ≥18 years completed health literacy measures without corresponding parent surveys. Adherence variables and health outcomes were obtained from medical records.

Results: Seventy-nine patients across two sites completed the study. Variance in classification of health literacy between measures was observed; however, most parents (82%-100%) scored within an "adequate literacy" range. More adolescents scored in lower health literacy ranges relative to the parents. Markers of SES were positively correlated with health literacy. Parent health literacy was negatively associated with biopsy-proven rejection episodes and the number of hospitalizations; however, it was not associated with measures of tacrolimus adherence. There were no relationships observed between parent and adolescent health literacy.

Conclusions: Health literacy is an important consideration in managing patient care; however, available measures demonstrate variability in capturing the skills of patients. Effective communication strategies may ameliorate admittedly small, but negative, impacts of limited health literacy on outcomes.

KEYWORDS

adherence, health literacy, health outcomes

Abbreviations: NVS, newest vital sign; SES, socioeconomic status; TOFHLA, test of functional health literacy in adults.

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1 | INTRODUCTION

Adherence to immunosuppressant medications is a critical factor in health outcomes among pediatric liver transplant recipients. Unfortunately, non-adherence to immunosuppressant medications is common in pediatric populations, with a prevalence ranging from 5% to 80%.[1] Non-adherence among pediatric transplant recipients is associated with a range of deleterious outcomes including graft loss, higher medical costs, and poor health-related quality of life.[1]

Among adults with chronic illness, health literacy has been shown to impact adherence and health outcomes.[2] Health literacy is "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions".[2] Conceptually, health literacy is a "constellation of skills"[2] and includes several discrete components including reading ability, quantitative analysis, and decision-making processes. In adults, limited health literacy is correlated with increased hospitalization rates,[2] decreased adherence,[3] and decreased overall health.[4] While many aspects of our current health care system are predicated on the assumption of adequate health literacy,[4] data suggest that approximately half of the nation's adults lack the prerequisite skills necessary to fully understand health information.[3] Conceptually, authors suggest several mechanisms to explain the link between limited health literacy and poor health outcomes[5,6] including limitations in interactions with providers, decreased adherence, and impaired use of healthcare systems. Much of the data supporting these models derive from adult populations and studies examining health literacy in a pediatric setting are limited. Data suggest associations between marginal health literacy of parents and poor health outcomes in children.[7] In addition, models based upon adult populations also address the need for assessing caregiver health literacy—an issue with specific importance to pediatric patients.[5] However, further investigations on health literacy in pediatric patients, as well as the impact on health literacy on adherence and health outcomes in pediatric populations, are needed to fully understand the extent of the associations.

The current project assesses the feasibility of administering health literacy measures in pediatric liver transplant recipients and their parents and examines the relationships between health literacy, adherence, and health outcomes. This population was of specific interest given that pediatric liver transplant recipients are relatively homogenous with respect to their regimen thereby minimizing regimen task variability and allowing for more clear analysis on adherence. This project is one of the first in pediatrics to measure health literacy and assess links with common outcomes within a specific population. In addition, it measures skills in both parents and patients—an important consideration given that most patients will eventually manage their condition on their own.

The specific aims of this project were to a. describe the health literacy skills of pediatric liver transplant recipients and their parents and b. examine correlations between health literacy skills and measures of adherence. It was hypothesized that a) parent and patient health literacy would be positively correlated and b) low patient and/or parent health literacy would be negatively correlated with adherence and health outcomes.

2 | PATIENTS AND METHODS

2.1 | Study Population

Eligible participants were recruited during regularly scheduled follow-up visits in the Pediatric Liver Transplant Clinics at two large Midwest children's hospitals. Inclusion criteria included the following: patient age ≥2 years, ≥12 months post-transplant and English as the primary language by both the patient and the parent.

2.2 | Procedures

This study was a cross-sectional assessment of the pediatric liver transplant population at two Midwest centers and was approved by the Institutional Review Boards of both institutions. Informed consent was obtained from parents/guardians for all participants <18 years of age and from participants who were ≥18 years. Informed assent was obtained for participants between the ages of 13-17 years. During a routine clinic visit, participants completed standardized assessment measures of health literacy. For patients ≤12 years, only the parent/guardian reports were obtained given that previous work used the TOFHLA only in patients aged 13 and older.[8] Measures of patient health literacy and parent/guardian health literacy were obtained for patients aged 13-17 years of age. For patients ≥ 18, only patient health literacy measures were obtained. Demographic, adherence, and health outcome data were obtained from a demographic survey and the patient's electronic medical records. Parents/guardians and patients were compensated for their time and effort devoted to study-related activities.

2.3 | Measures

2.3.1 | Health literacy

Two validated measures of health literacy were selected. As health literacy is a "constellation of skills,"[2] the selection of two measures allowed for assessment of multiple domains.

Test of Functional Health Literacy in Adults: The TOFHLA is a validated 67-item instrument for measuring health literacy. The TOFHLA has been used extensively in health literacy research, both in adult disease populations and among parents of pediatric patients.[9] Chisolm and Buchanan[8] also administered the TOFHLA to adolescents. Administration time averages 18-22 minutes.[10] The TOFHLA is divided into a 17-item numeracy section (TOFHLA-N) and a 50-item reading comprehension section (TOFHLA-R). The TOFHLA-N consists of orally administered questions requiring interpretation of pill bottle labels, appointment reminders, and insurance information.

Raw scores, based upon number of correct items, are converted to a weighted score from 0 to 50.

The TOFHLA-R consists of 3 "real world" passages from the healthcare setting. Passages include missing words and participants are required to select the word that best completes the sentences. For each blank, there are 4 possible word choices to complete the sentence. Scores range from 0 to 50 based on the number of correct words identified.

A total TOFHLA score from 0 to 100 is calculated from the addition of the TOFHLA-N weighted score and the TOFHLA-R score. Scores ranging from 0 to 59 suggest "inadequate functional health literacy," 60-74 suggests "marginal functional health literacy," 75-100 suggests "adequate functional health literacy."

The Newest Vital Sign (Pfizer): The NVS is a validated 6-item instrument for measuring health literacy. Administration time averages approximately 3 minutes.[10] The NVS includes orally administered questions requiring both comprehension and quantitative analysis. A standard nutritional label is shown to the participant, and all responses are based upon information on the label. The measure is scored by the number of questions answered correctly with possible scores from 0 to 6. Higher scores indicate higher health literacy. This score is also transformed into an interpretation where a score of 0-1 "suggests high (50% or more) likelihood of limited literacy," 2-3 "indicated the possibility of limited literacy," and 4-6 "almost always indicated adequate literacy."

NVS has been used less frequently than the TOFHLA. Validation studies found adequate psychometric properties and increased sensitivity relative to the TOFHLA in detecting marginal health literacy.[10]

2.3.2 | Adherence

Immunosuppressant levels: The degree of fluctuation in immunosuppressant blood levels has been used to assess the variability of medication administration, with higher fluctuations indicative of medication non-adherence.[11,12] To measure adherence to post-transplant immunosuppressant medications, data from routine monitoring of tacrolimus blood levels were obtained from the patient's medical record for the year prior to and the year after study participation. Immunosuppressant levels obtained during inpatient hospitalizations were excluded in analyses as they can reflect other processes outside of adherence (eg, acute illness).[13] Standard deviations (SD) of consecutive trough immunosuppressant blood levels were calculated. Based on previous studies of the association between immunosuppressant variability and risk for poor health outcomes, such as late allograft rejection, adherence was defined as a tacrolimus SD < 2.[13-16]

2.3.3 | Health outcomes

Measures of health outcomes included average values of liver function tests (AST, ALT, TBili), frequency, duration and reason for hospital admissions, liver biopsies, and rejection episodes. These measures were collected retrospectively from the patient's medical record for the year prior to and year after study participation. Results were separated into pre- and post-study as clinic staff often served as administrators of the measure. Conceptually, this lack of blinding to results may have changed interactions pre- and post-survey. To convey this limitation of the study appropriately, results were separated.

TABLE 1 Characteristics of patient population

Patient age	Mean/SD: 11.4 ± 5.5 y
<12 y old	55.6% (n = 40)
13-17 y old	28.2% (n = 20)
≥18 y old	16.9% (n = 12)
Patient gender	
Male	54.2% (n = 39)
Female	45.8% (n = 33)
Patient race/Ethnicity	
Caucasian	52.8% (n = 38)
African American	29.2% (n = 21)
Hispanic	1.4% (n = 1)
Asian	1.4% (n = 1)
Bi/Multiracial	2.8% (n = 2)
Did not report	12.5% (n = 9)
Age at transplant	4.3 ± 6.9 y
Time since transplant	8.1 ± 4.9 y
Parental respondent	
Mother	68.1% (n = 49)
Father	15.3% (n = 11)
Other	3.8% (n = 3)
Did not report	12.5% (n = 9)
Parental Respondent Age	Mean: 42.0 y (range: 21-63 y)
Parental Marital Status	
Single	20.8% (n = 15)
Married/Living with Partner	51.4% (n = 37)
Other	15.3% (n = 11)
Missing Data	12.5% (n = 9)
Parental Education	
8-11th grade	9.8% (n = 7)
Graduated high school	16.7% (n = 12)
Some college	36.1% (n = 26)
Earned Bachelors degree	19.4% (n = 14)
Completed graduate school	4.2% (n = 3)
Did not report	13.9% (n = 10)

2.3.4 | Statistical methods

Standard descriptive statistics including mean, standard deviation, and frequencies were calculated for patient demographics,

TABLE 2 Health literacy scores

Patient				
Measure	**Maximum Possible Score**	**Mean Score/SD**	**Classification**	**Percentage (n) of Respondents**
TOFHLA Numeracy Converted Score	50	38.1 ± 13.1		
TOFHLA Reading Comprehension Score	50	42.7 ± 7.6		
TOFHLA Total Score	100	80.8 ± 20.0	Inadequate (score = 0-59)	16.1% (n = 5)
			Marginal (score = 60-74)	3.2% (n = 1)
			Adequate (score (75-100)	80.6% (n = 25)
NVS Score	6	3.3 ± 1.8	High likelihood of limited literacy (score = 0-1)	18.8% (n = 6)
			Possibility of limited literacy (score = 2-3)	31.3% (n = 10)
			Adequate literacy (score = 4-6)	50.0% (n = 16)
Parent				
TOFHLA Numeracy Converted Score	50	46.0 ± 3.6		
TOFHLA Reading Comprehension Score	50	47.8 ± 2.1		
TOFHLA Total Score	100	93.8 ± 4.3	Inadequate (score = 0-59)	0.0% (n = 0)
			Marginal (score = 60-74)	0.0% (n = 0)
			Adequate (score (75-100)	100.0 (n = 60)
NVS Score	6	4.8 ± 1.6	High likelihood of limited literacy (score = 0-1)	6.7% (n = 4)
			Possibility of limited literacy (score = 2-3)	11.7% (n = 7)
			Adequate literacy (score = 4-6)	81.7% (n = 49)

health literacy measures, and health outcomes. Statistically significant correlations were determined by using Pearson (parametric) or Spearman's (non-parametric) correlations. All analyses were conducted using SPSS version 20.0 (IBM Corp. Released 2011. IBM SPSS Statistics for Windows, version 20.0. Armonk, NY: IBM Corp).

3 | RESULTS

3.1 | Participants

Data were collected from 79 patients. Approximately 3/4 of participants were from one center (n = 59; 74.6%). Five patients (6.3%) were on cyclosporine and 2 (2.5%) were on sirolimus with the remaining patients on tacrolimus (91.1%) as primary immunosuppressant. Due to debates in measuring adherence of patients with cyclosporine and sirolimus, they were excluded from analyses.

Table 1 describes the demographic characteristics of the participants used in analyses. Demographic information on marital status, parental (respondent) age, and parental education was not available for 9 patients (12.5%.). Five (6.9%) patients had undergone retransplantation. For these patients, the date of their first transplant was used for calculation of age at transplantation and time elapsed since transplantation.

Of the 72, 39 (54.2%) of the participants were aged 12 or under and only had parent report. Twenty (27.8%) participants were aged 13-18 and had both patient and parent report. Finally, 12 (16.7%) participants were over the age of 18 and had patient report only. One participant was within the range typically including both parent and patient report; however, the patient was unable to complete the measure due to problems understanding the measure. Therefore, only parent data were included in that analysis.

3.2 | Health Literacy

The parents had a mean score of 93.8 ± 4.3 on the TOFHLA and 4.8 ± 1.6 on the NVS. 100% of parents scored within the "adequate health literacy" range on the TOFHLA. 81.7% of parents scored within the "adequate literacy" range on the NVS. Patients had a mean score of 80.8 ± 20.0 on the TOFHLA and 3.3 ± 1.8 on the NVS

(Table 2). Fewer adolescents scored within the "adequate health literacy" classification on the TOFHLA (80.6%) and NVS (50.0%) relative to parents.

Neither measure of parent health literacy was significantly correlated with patient age or time since transplant. Patient health literacy scores on the NVS were significantly correlated with age in years at transplant (r = .41; P = .02) and time since transplant (r = −.43; P = .02). Significant correlations were not observed with patient scores on the TOFHLA and similar variables.

Parent and patient health literacy also demonstrated significant correlations with measures of SES. Parent NVS scores were positively correlated with both education level of the primary caregiver (r = .486; P = .000) and household income (r = .370; P = .004). The patient TOFHLA total scores were also significantly correlated with education level of the primary caregiver (r = .397; P = .027) and household income (r = .416; P = .020).

3.3 | Adherence and health outcomes

Adherence and health outcome data in the year prior to and after participation were available on all participants. Table 3 summarizes this data.

3.4 | Correlation between parent and patient measures of health literacy

Adolescent scores on both the TOFHLA and NVS were not significantly correlated with parent scores (P = .34 and P = .38, respectively).

TABLE 3 Health outcome variables pre- and post-study

Measure	1 year prior to study	1 year after study
Tacro SD	Average: 1.7 ± 1.3 ng/mL Tacro SD > 2.0: n = 20 (27.8%)	Average: 1.9 ± 1.5 ng/mL Tacro SD > 2.0: n = 26 (36.1%)
AST	Average: 50.6 ± 38.4	Average: 45.8 ± 32.0
ALT	Average: 50.8 ± 51.5	Average: 47.4 ± 48.0
TBili	Average: 0.9 ± 1.3	Average: 0.8 ± 1.1
% of participants hospitalized	23.9% (n = 17)	26.1% (n = 19)
% of participants requiring biopsies	16.9% (n = 12)	13.9% (n = 10)
% of participants with biopsy-proven rejection episodes	4.2% (n = 3)	1.4% (n = 1)

3.5 | Correlation between measures of health literacy, adherence, and health outcomes

Parent NVS scores were significantly correlated with number of biopsy-proven rejection episodes in the year prior to measure administration (r = −.27; P = .04) and number of hospitalizations in the year post-study (r = −.27; P = .04). The patient NVS scores were not significantly correlated with any measure of adherence or health outcome. Parent or patient TOFHLA scores were also not significantly correlated with any measure of adherence or health outcome.

4 | DISCUSSION

This project attempted to determine the feasibility of assessing health literacy in pediatric liver transplant recipients and their parents. A significant relationship between the health literacy of parents of pediatric liver transplant recipients and certain health outcomes was found. Specifically, biopsy-proven rejection episodes and hospitalizations were correlated with lower parental health literacy on one measure (NVS) but not another (TOFHLA) although this could be impacted by the limited variability in scores on the latter measure. Poor health outcomes are often associated with suboptimal adherence; however, significant associations were not seen between tacrolimus standard deviations and health literacy on either measure. *Parental health literacy and health outcomes.*

Based upon the existing literature, it would be expected that the impact of health literacy on health outcomes would be mediated by poor adherence; however, the data from the current study suggest a more direct route to poor health outcomes in pediatric patients who have parents with inadequate health literacy. Authors have suggested that several factors may mediate the relationship between limited health literacy and poor health outcomes including healthcare variables and provider-patient interactions as well as adherence.[5]

Overall, there was limited variability between parent health literacy scores. Increased variability in scores was observed with one measure (NVS) relative to the other (TOFHLA). Similar findings have been reported in the literature.[10,17] In the current study, the restricted range of scores occurred in the uppermost category of health literacy. That is, all parents using the TOFHLA met criteria for "adequate health literacy." The TOFHLA captures many of the skills encountered routinely during outpatient pediatric clinic visits including timing between medication dosages, understanding pharmacy instructions, and determining healthcare costs. In individual items, participant responses (eg, timing between dosages of medications) are judged correct if they fall within a wide range of acceptable answers. This is a particularly concerning problem within the transplant regimen given that timing between dosages (ie, 12 hour spacing) is critical for optimal health outcomes. Given that the answers on the TOFHLA could be correct, yet still reflect an incorrect practice, the TOFHLA scoring results in a potential overestimate of a patient's health literacy. In addition, the limited variability in scoring could mask any potential relationships between variables.

The limited statistically significant relationships identified in the current project also reflects that there may be practices in place within the clinics assessed that ameliorate the negative outcomes of impaired health literacy on adherence. Health literacy impairments may be addressed not only by improving education provided to parents and patients, but also by improving communication delivered by providers.[18,19] Within the clinics studied, strategies discussed in the literature including print materials, longer time spent in visits and routine access to clinical coordinators[19] are commonly employed and may buffer some pediatric patients from poor outcomes.

4.1 | Findings related to patient health literacy

Patient health literacy, as measured by the NVS, was positively correlated with patient age at transplant and negatively correlated with time since transplant. Data suggest that children with disease onset at younger ages are at higher risk for cognitive deficits relative to patients who have later disease progression[20] and may reflect need to direct health literacy–related interventions differently for those transplanted earlier in life.

Consistent with previous reports,[21] patient health literacy was not significantly related to adherence as measured by standard deviations of tacrolimus. This may be due, in part, to varying levels of parental involvement in their child's health care across patients. For those adolescents with high parental involvement, parental health literacy may be more crucial to understanding adherence relative to patients with low parental involvement. More striking was the wide variability in adolescent health literacy and its lack of relationship with parental health literacy. For a subgroup of adolescents, these data suggest that there may be inadequate transfer of necessary health information from parent to patient. Ultimately, this could result in an adolescent/young adult patient with deficient mastery of the self-management skills critical to managing their healthcare regimen.

In the oftentimes rocky transition of healthcare responsibility from parent to teen, adolescent patients may independently manage much of their regimen.[22] Data suggest that adolescent patients demonstrate inconsistencies in their self-management.[23] Deficits in health literacy skills may account for a portion of the inconsistencies. Such findings lay the groundwork for promoting the need for interventions addressing health literacy deficits in the pediatric population not only to improve the current health status of patients, but also their future skills as adult patients.

4.2 | Limitations

Limitations of this project include its recruitment from only two centers. Use of a small number of centers' patient population yield results that are directly impacted by center-specific variables (eg, personnel, educational strategies) that may either serve as a protective or risk factor. Further data from other pediatric liver transplant centers would enhance the generalizability of these results to other centers around the country and speak to whether the high levels of health literacy observed on the TOFHLA are specific to this population or a deficit of the measure itself.

A second limitation is the study's exclusion of non-English speaking families. Both the TOFHLA and NVS are available in Spanish and there has been work done to translate them to Arabic.[24] Previous work has raised concerns that the overall description of health literacy skills may be an overestimate due to the exclusion of non-English–speaking participants in many studies.[25] Specific to this study, there is risk to generalizability of this work to non-English–speaking patients and their families.

Another concern is the use of measures that have limited validation data in an adolescent population. To our knowledge, there is one paper reporting psychometric characteristics of the TOFHLA when completed by adolescents.[8] No papers were found reporting similar characteristics in the NVS. While problematic, it is a reflection of the current state of the literature and its strong focus on adult health literacy.

Finally, adherence behaviors may also not be completely captured by the single measure used: tacrolimus SD. That is, there may be other adherence behaviors (eg, making appointments; getting labwork done) more related to health literacy outside of taking medication. Both adherence and health literacy are multidimensional constructs. Given the relative lack of data in this area, it is possible that aspects of health literacy not measured in the current study may be differentially influencing adherence and outcomes.

4.3 | Future directions

While the impacts on outcomes were small, this project demonstrated the feasibility of studying health literacy in a pediatric liver transplant population. This novel area is understudied in adherence, especially among pediatric patients, and represents potential for new interventions within the clinic setting.

Further work is needed to fully understand both the measurement and impact of health literacy in pediatric transplant patients and their families. Future studies should focus on understanding health literacy in adolescents as they transition to more independent care. A crucial first step entails validation of existing measures or creation of ones that are appropriate for a pediatric/adolescent population. As the field moves ahead, reliance upon thoroughly researched measures to assess health literacy will be crucial. Second, identifying strategies to enhance patient adherence by addressing limitations in health literacy skills may provide another route to increase optimum health outcomes. Similar to other programs tied to modifiable risk factors for non-adherence, health literacy interventions have the potential to improve the current health outcomes of pediatric patients and prepare adolescents for a more active involvement in their health care as adults.

CONFLICTS OF INTEREST

None to report.

AUTHOR CONTRIBUTIONS

Dore-Stites and Fredericks developed the research plan directing this project. All authors contributed to data collection, analysis, and interpretation and the draft of the paper including critical revisions. All authors approved the final submission.

ORCID

Dawn Dore-Stites https://orcid.org/0000-0002-1240-4358
Emily M. Fredericks https://orcid.org/0000-0002-3110-4983

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How to cite this article: Dore-Stites D, Lopez MJ, Magee JC, et al. Health literacy and its association with adherence in pediatric liver transplant recipients and their parents. *Pediatr Transplant*. 2020;24:e13726. https://doi.org/10.1111/petr.13726