Published in final edited form as:

Pediatr Nephrol. 2018 October ; 33(10): 1759–1764. doi:10.1007/s00467-018-3962-y.

Parental Health Literacy and Progression of Chronic Kidney Disease in Children

Ana C. Ricardo¹, Lynn N. Pereira², Aisha Betoko², Vivien Goh¹, Amatur Amarah¹, Bradley A. Warady³, Marva Moxey-Mims⁴, Susan Furth⁵, and James P. Lash¹ on behalf of the Chronic Kidney Disease in Children (CKiD) Cohort Investigators

¹Division of Nephrology, University of Illinois, Chicago, IL

²Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

³Children's Mercy, Kansas City, Missouri

⁴National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, Bethesda, MD

⁵Division of Nephrology at The Children's Hospital of Philadelphia, Philadelphia, PA

Abstract

Background—Limited health literacy has been associated with adverse outcomes in children. We evaluated this association in the setting of chronic kidney disease (CKD).

Methods—We conducted a parental health literacy assessment of 367 children enrolled in the prospective multicenter observational Chronic Kidney Disease in Children (CKiD) Study. Using parametric failure-time models, we evaluated the association between parental health literacy and CKD progression, defined as time to the composite event of renal replacement therapy (RRT, dialysis or kidney transplant) or 50% decline in estimated glomerular filtration rate (eGFR). Parental health literacy was measured once using the Short Test of Functional Health Literacy (STOFHLA) that included two reading passages and four numeracy items (score range 0 to 100). Clinical and demographic characteristics of the cohort were measured at baseline.

Results—Median CKiD participant age was 9.5 years, 63% were male, and 59% non-Hispanic white. A glomerular diagnosis was present in 32% of participants. Median eGFR at baseline was 63 ml/min/1.73m², and median urine protein-to-creatinine ratio was 0.22. The median STOFHLA score was 98. Over a median follow-up of 3.7 years, the overall composite rate of RRT or 50% eGFR decline was 2.8 per 100 person-years. After adjustment for demographic and clinical

Corresponding author: Ana C. Ricardo, MD, 820 South Wood Street, 418W CSN, MC 793, Chicago, IL, 60612, Phone 312-996-8392, Fax 312-996-7378, aricar2@uic.edu.

Compliance with ethical standards

The study protocol was approved by the Institutional Review Boards at all participating sites and all participants gave written informed consent and/or assent.

Disclosures

None.

Financial Disclosure

The authors declare that they have no relevant financial interests.

factors, the relative time to CKD progression was 28% longer per 1 SD increase in STOFHLA score (Relative Time, 95%CI, 1.28, 1.06–1.53).

Conclusions—In this cohort of children with CKD, higher parental health literacy was associated with a nearly 30% longer time to the composite CKD progression outcome.

Keywords

Chronic kidney disease; health literacy; children

Introduction

Although children and adolescents constitute a small proportion of the chronic kidney disease (CKD) population[1], the potential impact of kidney disease progression on growth and development represents a unique challenge to the health care system and providers. This highlights the need to identify modifiable risk factors for the progression of kidney disease in children with CKD.

Health literacy is defined in Health People 2010 as: “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]. It is estimated that more than one-third of U.S. adults have limited health literacy skills[3]. In the general pediatric population, inadequate parental health literacy has been found to be associated with worse health outcomes such as poor diabetes control, increased emergency room visits, and hospitalizations for asthma[4]. However, to the best of our knowledge, there are no published studies exploring its impact on outcomes in children with CKD. The objective of this study is to evaluate the association of health literacy with CKD progression in the CKiD cohort.

Subjects and Methods

Study Population

The CKiD Study design, methods, and baseline characteristics of the cohort have been described previously[5, 6]. Children aged 1 to 16 years with an estimated glomerular filtration rate (eGFR) of 30 to 90 mL/min/1.73 m² were enrolled from 54 participating centers in the U.S. and Canada. The cohort was comprised of children with glomerular and non-glomerular disease. The primary glomerular diagnoses included focal segmental glomerulosclerosis and hemolytic uremic syndrome, while the primary non-glomerular diagnoses included obstructive uropathy, aplastic/hypoplastic/dysplastic kidneys, and reflux nephropathy. The study entry (baseline) visits occurred from January 2005 through March 2014, with subsequent annual follow-up visits.

Exposure Measures

Parental health literacy was measured once using the Short Test of Functional Health Literacy (STOFHLA). The STOFHLA assesses an individual's ability to read and understand health-related prose and documents, using actual materials that patients might encounter in the health care setting. The STOFHLA includes two reading passages and four numeracy items[7]. The two reading passages use the modified Cloze procedure; that is,

every fifth to seventh word in a passage is missing, and four multiple-choice options are provided.[8] Participants read the passage and select the multiple-choice option that best completes the blank. The first passage is selected from instructions written for patients receiving an upper gastrointestinal series (Gunning-Fog Index Readability grade 4.3) [9]; and the second passage comes from the patient's "Rights and Responsibilities" section of a Medicaid application form (Gunning-Fog Index readability grade 10.4). The reading comprehension section includes 36 multiple-choice items worth one point each, with higher scores indicating higher literacy levels. The numeracy section tests a patient's ability to comprehend directions on two prescription bottles, whether the blood glucose is within a normal range, and appointment instructions using an actual appointment slip. The numeracy score is multiplied by 7 (x 4 items) to create a score from 0 to 28, and each item in the reading comprehension is multiplied by 2 (x 36 items) to create a score from 0 to 72. The sum of the two sections yields the STOFHLA score, which ranges from 0 to 100. Scores from 0 to 55 indicate inadequate health literacy; scores from 56 to 66 indicate marginal health literacy, and scores from 67 to 100 indicate adequate health literacy[7]. The STOFHLA takes 12 minutes or less to complete, and it has been shown to have good internal consistency, reliability and validity compared with the long version of the Test of Functional Health Literacy in Adults and the Rapid Estimate of Adult Literacy in Medicine. [10–12] The STOFHLA was completed by the parents in the CKiD cohort between 2013 and 2015, in English or Spanish depending on their language of preference. A Spanish interpreter or a research coordinator fluent in Spanish was available to assist parents if needed. The STOFHLA It was also administered to participants over the age of 15. However, only parental health-literacy was evaluated in this study. Based upon prior literature which shows that health literacy is a stable construct over time[13], it was assumed that parental health literacy at the time of study entry was the same as when the STOFHLA was administered.

Outcome Measure and Definition

Our main outcome was CKD progression, defined as time to the composite event of renal replacement therapy (RRT, dialysis or kidney transplant) or 50% decline in estimated glomerular filtration rate (eGFR) from the baseline visit. An interpolation between the two GFR values surrounding the event was used to determine the eGFR halving point (i.e. point when the 50% decline in eGFR occurred). GFR was estimated using the CKiD Bedside Estimating Equation ($0.413 \times \text{height} / \text{serum creatinine}$)[14].

Covariates Assessment and Definition

CKiD participant data collected at the study entry included demographic information (age, gender, race, household income, and maternal education), health insurance, CKD diagnosis (glomerular or nonglomerular), blood pressure (BP), body mass index (BMI), birth history, and laboratory markers. Age was calculated both at study entry and at the time of CKD onset. Maternal education, household income, and health insurance status were all self-reported via a questionnaire administered at the study visit. Maternal education was categorized as attainment of high school education or less, some college, or college and above, household income as greater than \$36,000 or \$36,000 and health insurance status as having private-based insurance (i.e. private plan from employer or purchased directly) or

non-private-based insurance. Casual systolic and diastolic BP were obtained by a trained examiner using an aneroid sphygmomanometer. Three measurements are taken at the visit and then averaged to determine the casual blood pressure. Hypertension was defined as systolic or diastolic BP > 90th percentile for age, sex, and height. BMI age-sex-specific standard deviation scores (z-scores) were determined based on the Center of Disease Control growth charts. Premature birth was defined as gestational age <36 weeks; small for gestational age as birth weight below the 10th percentile for gestational age; and low birth weight as weight < 2,500 g. CKD-related laboratory markers such as serum creatinine and albumin were measured at the central CKiD laboratory at the University of Rochester. Details of the techniques used to measure the first morning urine protein and creatinine have been published elsewhere[15]. Proteinuria was defined as a urine protein/creatinine ratio greater than 0.2 g/g. Dyslipidemia was defined as serum triglycerides > 130 mg/dL, HDL-C < 40 mg/dL or non-HDL-C > 160 mg/dL.

Statistical Analyses

Baseline demographic and clinical characteristics of the cohort were reported as median values with interquartile range (IQR), or frequencies and percentages, as appropriate. Parental health literacy scores were compared by race (white vs. nonwhite) and maternal education (high school education or less, some college, or college and above) using the Wilcoxon rank-sum test. In failure-time analyses, the proportionality assumption of the Cox regression models was not met. Therefore, we used accelerated parametric failure-time models assuming a lognormal distribution to evaluate the impact of parental health literacy scores on time to the composite endpoint of either 50% decline in GFR or RRT initiation. Relative times were used to quantify the strength of the association. Specifically, relative times correspond to the time it takes for a proportion of the exposed group (lower STOFHLA score) to experience the composite event, divided by the time it takes for an equal proportion of the unexposed group (higher STOFHLA score) to experience the event. STOFHLA score was modeled as a continuous variable and rescaled by dividing the original score by its standard deviation to facilitate interpretation of the results. All relative times from the lognormal models therefore reflected one standard deviation difference in the main exposure. The first model was unadjusted. Potential confounding effects of clinical center, baseline age, gender and race were accounted for in the second model. The third model additionally adjusted for baseline clinical factors including eGFR, proteinuria, glomerular diagnosis, age at CKD onset, hypertension, body mass index (BMI) z-score, small-for-gestational age, albumin, and dyslipidemia. Lastly, variables of baseline maternal education, income, and private health insurance were incorporated in the final model. Statistical analyses were carried out using SAS 9.4 (SAS Institute, Cary, NC). Figures were created on TIBCO Spotfire S+ 8.2 for Windows. All tests were two-sided and a P value of <0.05 was considered statistically significant.

Results

Baseline Characteristics

By 2015, parental (mother or father) health literacy data was available for 367 CKiD participants. In addition, there were 51 CKiD participants older than 15 years who

completed the STOFHLA, but no parental health literacy data was available, therefore, these participants were not included in the analysis. Median (IQR) age was 9.5 (6.1,13.4) years and 63% were male, 59% were of non-Hispanic white race, 18% were non-Hispanic African American, 13% were Hispanic, and 10% were other racial/ethnic group (Table 1). Additional characteristics of the cohort included annual household income >\$36,000 in 62%, maternal education of college level and above in 36%, and health insurance in 99% of the participants. CKD was attributed to a glomerular disease in 32% of the participants, median (IQR) eGFR was 63 (51, 79) ml/min/1.73m², and median (IQR) urine protein/creatinine ratio was 0.22 (0.09, 0.64). Sixty percent were taking an anti-hypertensive and 51% were on angiotensin converting enzyme-inhibitor or angiotensin receptor blocker. Low birth weight was reported in 20% of participants and 11% were reported to be premature.

The median (IQR) STOFHLA score was 98 (93–100), and the minimum score was 17. The distribution of parental STOFHLA scores varied by race/ethnicity (Figure 1a) and maternal education (Figure 1b). The median (IQR) STOFHLA score was significantly higher for whites [100 (96–100)] versus non-whites [98 (91–100), $p<0.0001$] and for those with maternal education levels above high school [100 (96–100)] versus high school level or below [96 (89–100), $p<0.0001$].

Association of Health Literacy with CKD Progression

Over a median (IQR) follow-up of 3.7 (2.9, 7.1) years, there were 46 composite events and the overall event rate was 2.8 per 100 person-years. Of the 46 participants with the composite outcome, 3 had transplant, 1 started dialysis and 42 had reached 50% decline in eGFR. Results of multivariable models are presented in the Table 2. In unadjusted analyses, the relative time [RT, 95% (confidence interval)] to CKD progression was 1.32 (1.15, 1.50), or 32% longer per 1 standard deviation (SD) increase in STOFHLA score. This point estimate did not change significantly after adjustment for demographic and clinical variables (RT 1.28; 95% CI 1.06, 1.53). The SD of the STOFHLA score was 9.7.

Discussion

Overall, we found that parental health literacy for the cohort was very high. However, we found that certain vulnerable groups including racial minorities and parents with lower educational attainment were more likely to have lower health literacy. On longitudinal analyses, we found that higher parental health literacy was associated with slower CKD progression, independent of sociodemographic and clinical factors. These findings suggest that lower health literacy represents an under-recognized risk factor for CKD progression which is potentially modifiable.

A recent systematic review of the literature concluded that inadequate parental health literacy is associated with worse health outcomes in children including poor diabetes control, more emergency room visits, and hospitalizations for asthma[4]. However, it has not been extensively studied in the context of non-dialysis CKD. In a recent study of children with CKD, Rak et al found that a lower caregiver word reading literacy was associated with a higher incidence of emergency room visits[16]. Our study is the first to examine and observe a significant association of higher health literacy with slower CKD progression.

Low health literacy may contribute to poor health outcomes through various mechanisms. For example, understanding of disease, adherence to treatment, and self-management represent challenges for those with limited health literacy[17–20]. In addition, low literate individuals with chronic disease may have difficulty communicating with health care providers, which is essential to process disease information and carry out instructions regarding diet, physical activity, and medication use. Consequently, low health literacy may lead to poor control of CKD risk factors.

Our findings suggest that efforts to incorporate an assessment of health literacy into practice and to modify patient-provider communication based on this assessment, may lead to improvements in health outcomes for children with CKD. In addition, future evaluation of literacy-sensitive interventions, such as low literacy disease-specific educational material[21], might also contribute to improve the health of children with CKD, as has been shown in children with asthma and adults with chronic obstructive pulmonary disease and heart failure[22–24].

Our results should be interpreted in light of the following limitations. First, parental health literacy was not assessed at study entry. However, prior literature suggests that health literacy is stable over time[13]. Second, we cannot establish causality as is the case with most observational studies.[25] Finally, we did not measure potential mediators of the association between health literacy and CKD such as disease knowledge and self-efficacy. Nevertheless, our study had several strengths including the large sample of children with CKD of broad etiologies with longitudinal follow-up.

In conclusion, we found that higher parental health literacy was associated with slower CKD progression. This finding is important because interventions addressing parental health literacy have the potential to positively impact health outcomes in children with CKD.

Acknowledgments

Support

The CKiD Cohort Study was supported by the Funding was provided by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and the National Heart, Lung, and Blood Institute (U01-DK-66143, U01-DK-66174, U01-DK-082194, U01-DK-66116). Dr. Ricardo is funded by the NIDDK K23-DK-094829 Award. Dr. Lash is funded by the NIDDK K24-DK-092290 Award.

References

1. [Accessed 4 Jan 2017] Chronic Kidney Disease (CKD) Surveillance Project. <https://nccd.cdc.gov/ckd/detail.aspx?QNum=Q245>
2. Read “Health Literacy: A Prescription to End Confusion” at NAP.edu
3. [Accessed 4 Jan 2017] America’s Health Literacy: Why We Need Accessible Health Information. <https://health.gov/communication/literacy/issuebrief/>
4. DeWalt DA, Hink A. Health literacy and child health outcomes: a systematic review of the literature. *Pediatrics*. 2009; 124(Suppl 3):S265–274. [PubMed: 19861480]
5. Furth SL, Cole SR, Moxey-Mims M, Kaskel F, Mak R, Schwartz G, Wong C, Muñoz A, Warady BA. Design and methods of the Chronic Kidney Disease in Children (CKiD) prospective cohort study. *Clin J Am Soc Nephrol*. 2006; 1:1006–1015. [PubMed: 17699320]

6. Furth SL, Abraham AG, Jerry-Fluker J, Schwartz GJ, Benfield M, Kaskel F, Wong C, Mak RH, Moxey-Mims M, Warady BA. Metabolic abnormalities, cardiovascular disease risk factors, and GFR decline in children with chronic kidney disease. *Clin J Am Soc Nephrol*. 2011; 6:2132–2140. [PubMed: 21841064]
7. Baker DW, Williams MV, Parker RM, Gazmararian JA, Nurss J. Development of a brief test to measure functional health literacy. *Patient Educ Couns*. 1999; 38:33–42. [PubMed: 14528569]
8. Taylor WL. Cloze procedures: A new tool for measuring readability. *JMCQ*. 1953; 30:415–433.
9. Gunning R. *The Technique of Clear Writing*. McGraw Hill; New York, NY: 1968.
10. Baker DW, Gazmararian JA, Williams MV, Scott T, Parker RM, Green D, Ren J, Peel J. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *Am J Public Health*. 2002; 92:1278–1283. [PubMed: 12144984]
11. Parker RM, Baker DW, Williams MV, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med*. 1995; 10:537–541. [PubMed: 8576769]
12. Davis TC, Long SW, Jackson RH, Mayeaux EJ, George RB, Murphy PW, Crouch MA. Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Fam Med*. 1993; 25:391–395. [PubMed: 8349060]
13. Baker DW. The meaning and the measure of health literacy. *J Gen Intern Med*. 2006; 21:878–883. [PubMed: 16881951]
14. Schwartz GJ, Muñoz A, Schneider MF, et al. New equations to estimate GFR in children with CKD. *J Am Soc Nephrol*. 2009; 20:629–637. [PubMed: 19158356]
15. Wong CS, Pierce CB, Cole SR, Warady BA, Mak RH, Benador NM, Kaskel F, Furth SL, Schwartz GJ. CKiD Investigators. Association of proteinuria with race, cause of chronic kidney disease, and glomerular filtration rate in the chronic kidney disease in children study. *Clin J Am Soc Nephrol*. 2009; 4:812–819. [PubMed: 19297612]
16. Rak EC, Hooper SR, Belsante MJ, Burnett O, Layton B, Tauer D, Mantoo B, DeWalt D, Ferris ME. Caregiver word reading literacy and health outcomes among children treated in a pediatric nephrology practice. *Clin Kidney J*. 2016; 9:510–515. [PubMed: 27274841]
17. Devraj R, Gordon EJ. Health literacy and kidney disease: toward a new line of research. *Am J Kidney Dis Off J Natl Kidney Found*. 2009; 53:884–889.
18. Macabasco-O'Connell A, DeWalt DA, Broucksou KA, Hawk V, Baker DW, Schillinger D, Ruo B, Bibbins-Domingo K, Holmes GM, Erman B, Weinberger M, Pignone M. Relationship between literacy, knowledge, self-care behaviors, and heart failure-related quality of life among patients with heart failure. *J Gen Intern Med*. 2011; 26:979–986. [PubMed: 21369770]
19. Kalichman SC, Pope H, White D, Cherry C, Amaral CM, Swetzes C, Flanagan J, Kalichman MO. Association between health literacy and HIV treatment adherence: further evidence from objectively measured medication adherence. *J Int Assoc Physicians AIDS Care Chic Ill* 2002. 2008; 7:317–323.
20. Wright Nunes JA, Wallston KA, Eden SK, Shintani AK, Ikizler TA, Cavanaugh KL. Associations among perceived and objective disease knowledge and satisfaction with physician communication in patients with chronic kidney disease. *Kidney Int*. 2011; 80:1344–1351. [PubMed: 21832984]
21. Morrison AK, Myrvik MP, Brousseau DC, Hoffmann RG, Stanley RM. The relationship between parent health literacy and pediatric emergency department utilization: a systematic review. *Acad Pediatr*. 2013; 13:421–429. [PubMed: 23680294]
22. Robinson LD, Calmes DP, Bazargan M. The impact of literacy enhancement on asthma-related outcomes among underserved children. *J Natl Med Assoc*. 2008; 100:892–896. [PubMed: 18717138]
23. Kiser K, Jonas D, Warner Z, Scanlon K, Shilliday BB, DeWalt DA. A randomized controlled trial of a literacy-sensitive self-management intervention for chronic obstructive pulmonary disease patients. *J Gen Intern Med*. 2012; 27:190–195. [PubMed: 21935752]
24. Baker DW, DeWalt DA, Schillinger D, Hawk V, Ruo B, Bibbins-Domingo K, Weinberger M, Macabasco-O'Connell A, Pignone M. "Teach to goal": theory and design principles of an intervention to improve heart failure self-management skills of patients with low health literacy. *J Health Commun*. 2011; 16(Suppl 3):73–88. [PubMed: 21951244]

25. Kovesdy CP, Kalantar-Zadeh K. Observational studies versus randomized controlled trials: avenues to causal inference in nephrology. *Adv Chronic Kidney Dis.* 2012; 19:11–18. [PubMed: 22364796]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Figure 1. Distribution of parental Short Test of Functional Health Literacy (STOFHLA) scores by a) Race, and b) maternal education

Table 1

Baseline Clinical and Demographic Characteristics of 367 CKiD participants for whom the STOFHLA was completed by a parent (mother or father)

Variables	Number (%) or median [IQR]
Age, years	9.5 [6.1, 13.4]
Gender, male	231 (63)
Race	
Non-Hispanic white	218 (59)
African American	66 (18)
Hispanic	47 (13)
Other	36 (10)
Maternal age, years	36.7 [31.7, 43.0]
Household income >\$36,000	224 (62)
Maternal education	
High school or less	122 (34)
Some college	109 (30)
College and above	127 (36)
Maternal Employment Status	
Working full-time	166 (45)
Working part-time	78 (21)
Unemployed, seeking work	24 (7)
Unemployed, not seeking work	68 (19)
Student	9 (2)
Retired	7 (2)
On disability	13 (4)
Household Structure	
Three people or less in household	124 (34)
More than two children (under 18 years of age)	116 (38)
Marital status of parents	
Married/living together	241 (68)
Language spoken by the parent most frequently	
English	343 (94)
Spanish	12 (3)
Both English and Spanish	9 (2)
Health Insurance	
Any	361 (99)
Private-based	226 (63)
CKD status	
Glomerular diagnosis	119 (32)
Age at CKD diagnosis, years	1.4 [0, 6.5]
eGFR, ml/min/1.73m ²	63 [51, 79]
Urine protein to creatinine ratio, mg/mg	0.22 [0.09, 0.64]

Variables	Number (%) or median [IQR]
CVD Status	
Systolic BP percentile (for age, sex, height)	60 [34, 84]
Diastolic BP percentile (for age, sex, height)	69 [45, 87]
Hypertension	99 (28)
Body mass index z-score (for age, sex)	0.67 [−0.15, 1.44]
Low birth weight (< 2,500 g)	69 (20)
Small for gestational age	67 (20)
Premature	38 (11)
Medications	
Steroids	43 (12)
ACEI or ARB	188 (51)
Any antihypertensive	222 (60)
Laboratory	
Calcium, mg/dL	9.5 [9.2, 9.8]
Phosphate, mg/dL	4.4 [4.0, 4.9]
Albumin, g/dL	4.4 [4.2, 4.6]
Hemoglobin percentile (for age, sex, race)	40 [8, 79]
Dyslipidemia	135 (37)

CKiD Chronic Kidney Disease in Children, *STOFHLA* Short Test of Functional Health Literacy, *CKD* chronic kidney disease, *CVD* cardiovascular disease, *eGFR* estimated glomerular filtration rate, *BP* blood pressure, *ACEi* angiotensin converting enzyme-inhibitor, *ARB* angiotensin receptor blocker

Table 2

Relative Time to CKD progression event (time to the composite event of renal replacement therapy or 50% decline in estimated glomerular filtration rate per one standard deviation increase in STOFHLA

Relative Time (95% CI)	
Model 1	1.32 (1.15, 1.50)
Model 2	1.26 (1.11, 1.42)
Model 3	1.29 (1.13, 1.48)
Model 4	1.28 (1.06, 1.53)

Model 1: Unadjusted

Model 2: Model 1 plus clinical center, baseline age, gender, race.

Model 3: Model 2 plus baseline eGFR, proteinuria, glomerular diagnosis, age at CKD onset, hypertension, BMI z-score, small for gestational age, albumin, dyslipidemia.

Model 4: Model 3 plus baseline maternal education, income, health insurance.

CKD chronic kidney disease, *STOFHLA* Short Test of Functional Health Literacy, *eGFR* estimated glomerular filtration rate, *BMI* body mass index