



ORIGINAL ARTICLE

Caregiver word reading literacy and health outcomes among children treated in a pediatric nephrology practice

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Abstract

Background: Caregivers play a major role in the healthcare of pediatric patients, particularly during childhood and adolescence. This study examined the impact of caregivers' functional literacy on the health outcomes of adolescents with chronic kidney disease (CKD) or end-stage kidney disease (ESKD).

Methods: Caregiver-child dyads in a Southeastern US pediatric nephrology clinic participated in this cross-sectional study. We collected demographic information, data on caregivers' functional literacy skills (Wechsler Individual Achievement Test Word Reading Subtest) and child health outcomes (healthcare utilization and adherence). Negative binomial regression analyses were used to test the relationships.

Results: A total of 98 pediatric patients and their caregivers participated. Caregivers' word reading literacy was associated with their children's healthcare utilization. Patients whose caregivers had lower word reading literacy skills (<7th grade) had greater incidence of emergency room (ER) visits (adjusted incidence rate ratio = 2.05, 95% confidence interval: 1.007, 4.177, $P < 0.05$) after adjusting for major demographic factors. Patients' hospitalization rates and adherence to medication/diet/appointments were comparable in the two groups.

Conclusions: Low caregiver functional word reading literacy was negatively related to health outcomes of adolescents with CKD/ESKD as reflected by greater ER visits. Educational materials and teaching strategies (dialysis training protocols, patient education materials) adjusted for low literacy levels may contribute to better outcomes.

Key words: chronic renal failure, CKD, dialysis, pediatrics, peritonitis

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Introduction

Chronic kidney disease (CKD) is a progressive condition manifested in decline in renal function to the point of kidney failure, which requires renal replacement therapy (dialysis or kidney transplantation). Pediatric CKD patients and their caregivers learn intricate and elaborate procedures for disease management [1]. With decline in kidney function, treatment regimens become more complex, involving an increased number of medications and injectables (e.g., growth hormone) [1], dietary modifications, and weight and blood pressure monitoring. In some end-stage kidney disease (ESKD) cases, home-based dialysis is needed until a transplant becomes available. Even after transplant, the complex treatment and visits to medical facilities continue. The health management of children with CKD/ESKD is a major burden, and its success is highly contingent on the capabilities of the caregiver. Many patient/family education materials are presented in written form, thus demanding functional literacy for adequate comprehension of those materials.

Literacy denotes the ability to read and write and is often judged against standards at a particular school grade level. American adults are more educated than ever [2], yet many struggle with low literacy [3, 4]. Youth and adolescents have similar challenges, with at least one in three having low health literacy [5]. Individuals with low literacy skills face multiple challenges in tasks that require synthesizing and integrating information from lengthy texts or the ability to perform mathematical tasks involving two or more sequential operations. These challenges lead to struggles with daily functioning, particularly in tasks that involve problem solving [3].

Low literacy is associated with higher rates of hospitalizations and emergency care, lower participation in preventive care, worse medication adherence, poorer ability to interpret labels and health messages, poorer overall health status and higher mortality rates in older adults [6, 7]. Adult patients with low literacy are 3.4 times less likely to interpret prescription medication warning labels correctly [8]. They are also more prone to making errors in dosing medications using nonstandard measurement instruments [9] and experience difficulties understanding nutrition labels [10]. Adults with low literacy are 1.2–4 times more likely to exhibit negative health behaviors that affect their child's health and twice as likely to use health services for the child [5]. The consequences of low literacy include medical noncompliance and medication errors [11, 12], difficulties with complicated medical regimens and self-care [6, 8] and increased risk for hospitalization [13]. In addition, the skills needed to effectively navigate the healthcare system are also compromised [13].

Low parent literacy has been shown to predict worse health outcomes among children with chronic health conditions, such as asthma [14] and diabetes [15], but it has not been studied in pediatric patients with CKD/ESKD. Pediatric patients have complex treatment regimens, so consequences of nonadherence pose a serious concern for health and growth. Understanding the effects of literacy is also highly relevant for medical practice. Information on literacy levels can guide modifications in phrasing and delivering medical instructions and directives to caregivers and hopefully can improve medical care for persons with chronic illnesses.

The primary objective of this study was to examine associations of caregivers' functional literacy skills with their child's health outcomes of adherence to medications, diet, appointments, hospitalizations and emergency room (ER) visits. We hypothesized that pediatric patients with CKD/ESKD whose caregivers have low functional literacy skills will experience worse

health outcomes as reflected in higher rates of healthcare utilization (more ER visits and hospitalizations) and poor adherence to medications, appointments or diet.

Materials and methods

Participants and procedure

Caregivers of patients treated in a pediatric nephrology practice participated in this cross-sectional study. Data were collected in a large, tertiary southeastern medical center. The clinic's registry was used to identify potential participants. Eligibility criteria included caregivers of pediatric patients who had CKD, ESKD (dialysis or transplant), congenital anomalies of the kidneys and urinary tract (with normal kidney function), and/or hypertension and who were receiving at least one medication daily. We excluded people who could not read English. Two trained research assistants collected the data from consecutive patients who attended the clinic. The participants were approached at the time of the clinic visit, and completed the tests after their visit with the doctor. This research was approved by the university's Institutional Review Board and appropriate consent/assent forms were obtained prior to participation.

Measures

Literacy

Caregivers' functional literacy was assessed with the Wechsler Individual Achievement Test (WIAT-II™) Word Reading Subtest. The Word Reading Subtest is a standardized individual assessment of reading decoding skills. The instrument is normed and has good psychometric properties (Cronbach's α between 0.80 and 0.98, and test-retest reliabilities of 0.85–0.95). This measure was selected to allow for assessment of literacy skills applicable in a broader range of settings, beyond those necessary in the healthcare environment. Grade-based, norm-referenced scores were computed (referring the individual's performance to others of the same age and the same grade completion level). For the purpose of this analysis and based on literature review, we used a cut-point score of 7th grade reading literacy skills to group caregivers into adequate literacy versus low literacy groups. In general, adult caregivers of pediatric patients with less than a 7th grade reading level were deemed functionally illiterate and reportedly encounter significant challenges with medical instructional materials due to these limitations [16, 17]. Education level was established by the caregivers reporting their last completed year in school and used as a continuous variable.

Health outcomes

A separate questionnaire was administered to all caregivers to obtain sociodemographic information, travel distance to the pediatric nephrology practice and the phone number of their pharmacy to determine adherence to treatment based on medication possession ratios [18]. Comprehensive medical records from the hospital and its dialysis unit electronic database were abstracted to obtain additional medical information.

One of the outcomes included adherence to treatment using the medication refill rate in the last 6 months (as a dichotomous variable). Because most patients with CKD have hypertension, we chose a definition of adherence used in a population-based study of patients refilling antihypertensive agents (i.e. $\geq 80\%$ of times) [19]. If all the prescription medications (e.g. antihypertensives, phosphorus binders and antirejection agents) were refilled

≥80% of the time, the participant was deemed adherent. Patients with a renal transplant were determined to be adherent to the calcineurin inhibitor if the levels were at the expected therapeutic ranges ≥80% of the time for the preceding 6 months. Patients were determined adherent to appointments if they attended 80% or more of their scheduled visits with their provider (dichotomous variable). Adherence to diet was based on patients' self-report to the dietician (low sodium) or phosphorus levels at normal range for age based on KDOQI guidelines (dichotomous variable). Health providers who computed adherence rates were blinded to the word reading literacy test results. The number of ER visits and hospitalizations in the last year were obtained from both the electronic health record and by parent report.

Data analyses

Univariate and multivariate analyses were employed to describe the sample and identify associations among sociodemographic variables (age, race/ethnicity, educational level and sex) and outcome measures (patients' adherence to diet, medication and appointments, hospitalizations and ER visits). We performed χ^2 tests for categorical variables and t-tests for continuous measures. To assess the association of the main predictor (caregivers' functional literacy) and outcome measures, we tested negative binomial regression models for counts to correct the overdispersion identified in Poisson regression (hospitalizations and ER visits) and χ^2 tests on the dichotomous outcomes (adherence to medication, diets and appointments).

To answer our main question, is caregivers' functional literacy associated with health outcomes of pediatric patients, we employed multivariate analysis. Two negative binomial regression models were tested for two dependent variables, ER visits and hospitalizations. In these analyses, we adjusted for pediatric patient's age, race, sex, diagnosis and caregiver's age. Significance was determined at $P < 0.05$ for all analyses. SPSS Statistics 22 was used to analyze the data.

Results

Participant characteristics

We invited 104 caregiver-child dyads to participate. A total of 98 dyads completed the study (94% participation rate). Lack of time was the main reason for declining participation. Most caregivers tested were female (72%). Patients' condition/treatment modality included CKD Stages 2-4 ($n = 52$), kidney transplant ($n = 25$) and peritoneal dialysis ($n = 21$). In terms of race/ethnicity, 47 (48%) participants were non-Hispanic white, 41 (41.8%) were African American and 10 (10.2%) were Hispanic. Mean (\pm SD) caregiver age was 41.36 years \pm 10.84 (range: 18.77-77.00), and their mean level of educational attainment was 12.77 years \pm 2.67 (range: 6-24, SD). The mean age for pediatric patients was 12.75 years \pm 4.62 (range: 0.82-21.32, SD).

Patients had diverse socioeconomic backgrounds, and came to the clinic from urban, suburban and rural areas of the state, traveling on average 85.1 miles \pm 50.25 (range: 1-234 SD) each way to receive medical care. Their diagnoses and demographic characteristics are depicted in Table 1.

The mean caregiver grade equivalence of our cohort was 9.74 \pm 2.98. The caregiver mean word reading standard score [$X = 100$, standard deviation (SD) = 15] for the entire sample was 88.9 \pm 19.3. The mean grade equivalence level was significantly higher in individuals of non-Hispanic white race compared with other minorities, $t = -3.95$, $P < 0.001$. The word

Table 1. Participant characteristics by parents' WIAT-II™ word reading literacy scores

	<7th grade reading (n = 23)	≥7th grade reading (n = 75)
Child's sex		
Male (%)	10 (43.5)	39 (52.0)
Female (%)	13 (56.5)	36 (48.0)
Child's race		
Non-Hispanic White (%)	7 (30.4)	40 (53.3)
African American (%)	15 (65.2)	26 (34.7)
Hispanic/other (%)	1 (4.4)	9 (12.0)
Child's diagnosis		
Peritoneal dialysis (%)	7 (30.4)	14 (18.7)
Kidney transplant (%)	8 (34.8)	17 (22.7)
CKD/hypertension (%)	8 (34.8)	44 (58.7)
Insurance		
Private (%)	2 (8.7)	36 (48.0)
Public (%)	21 (91.3)	34 (45.3)
Self-pay (%)	0 (0.0)	5 (6.7)
Distance from home, mean miles (SD)	82.30 (52.62)	85.91 (49.84)
Child's age, mean number of years (SD)	13.30 (4.76)	12.59 (4.60)
Caregiver's age, mean number of years (SD)	44.83 (15.06)	40.28 (9.02)
Caregiver's level of educational attainment, mean number of years of school completed ^a (SD)	10.96 (2.14)	13.32 (2.58)

Ns vary due to missing data.

^aSignificant differences based on t-test results, $P < 0.005$.

Table 2. Adherence to medication, appointments and diet

	<7th grade reading (n = 23), N (%)	≥7th grade reading (n = 75), N (%)
Medications		
Yes	17 (81.0)	66 (93.0)
No	4 (19.0)	5 (7.0)
Appointments		
Yes	18 (85.7)	68 (94.4)
No	3 (14.3)	4 (5.6)
Diet		
Yes	13 (76.5)	58 (90.6)
No	4 (23.5)	6 (9.4)

Ns vary due to missing data.

reading standard score also differed among the different racial/ethnic groups with a mean of 96.20 \pm 16.10 for non-Hispanic whites versus 82.12 \pm 19.70 for minorities ($t = -3.81$, $P < 0.001$).

Child's diagnosis and adherence to medication, appointments and diet

Caregiver's functional literacy was not related to child's condition/treatment modality ($P = 0.13$), or to any child adherence measures assessed: medications ($P = 0.10$), diet ($P = 0.12$) or nephrology appointments ($P = 0.18$). Over 90% of pediatric patients who had caregivers with adequate literacy were determined to be adherent to medication, appointments and diet. Children of low literacy caregivers were also adherent, with at least three out of four being compliant with medication, appointments and diet (Table 2).

Table 3. Predicting child hospitalizations using negative binomial regression (*adjusted IRRs)

	B	SE	Wald χ^2	Sig.	IRR	95% CI
Child race: minority ^a	0.295	0.349	0.713	0.398	1.343	0.667–2.662
Child gender: male ^b	0.278	0.338	0.679	0.410	1.321	0.681–2.559
Child age	–0.004	0.042	0.008	0.929	0.996	0.918–1.081
Parent/caregiver age	–0.003	0.019	0.032	0.859	0.997	0.961–1.034
Peritoneal dialysis ^c	0.885	0.413	4.592	0.032	2.423	1.078–5.444
Kidney transplant ^c	0.494	0.389	1.618	0.203	1.639	0.765–3.511
Private insurance ^d	–0.188	0.414	0.207	0.649	0.828	0.368–1.866
Parent literacy (<7th grade) ^e	0.452	0.399	1.281	0.258	1.571	0.719–3.435
Intercept	–0.490	0.827	0.351	0.554	0.613	0.121–3.098

SE, standard error. Hospitalizations: likelihood ratio χ^2 statistic = 12.58, df = 8, P = 0.127.

Reference group: ^aNon-Hispanic White, ^bFemale, ^cCondition/treatment modality: CKD, ^dHealth insurance: public/self-pay, ^e≥7th grade.

Table 4. Predicting child ER visits using negative binomial regression (*adjusted IRRs)

	B	SE	Wald χ^2	Sig.	IRR	95% CI
Child race: minority ^a	0.260	0.329	0.621	0.431	1.296	0.680–2.473
Child gender: male ^b	0.188	0.303	0.387	0.534	1.207	0.667–2.184
Child age	–0.019	0.040	0.231	0.631	0.981	0.906–1.061
Parent/caregiver age	–0.003	0.015	0.052	0.820	0.997	0.968–1.026
Peritoneal dialysis ^c	0.395	0.389	1.032	0.310	1.485	0.693–3.184
Kidney transplant ^c	0.210	0.368	0.327	0.568	1.234	0.600–2.536
Private insurance ^d	–0.052	0.371	0.019	0.890	0.950	0.459–1.966
Parent literacy (<7th grade) ^e	0.718	0.363	3.918	0.048	2.051	1.007–4.177
Intercept	–0.131	0.660	0.039	0.843	0.877	0.240–3.200

SE, standard error. ER visits: likelihood ratio χ^2 statistic = 11.009, df = 8, P = 0.201.

Reference group: ^aNon-Hispanic White, ^bFemale, ^cCondition/treatment modality: CKD, ^dHealth insurance: public/self-pay, ^e≥7th grade.

Parental functional word reading literacy and child's healthcare utilization

In univariate analysis, we observed no differences in hospitalization rates between patients who had caregivers with low and adequate functional literacy. Caregiver literacy scores were significantly associated with pediatric patients' ER visits [unadjusted incidence rate ratio (IRR) = 2.32, 95% confidence interval (95% CI): 1.26, 4.25], and incidence of hospitalizations was comparable (unadjusted IRR = 1.86, 95% CI: 0.94, 3.68).

We conducted multivariate tests with hospitalizations and ER visits using negative binomial regression, the recommended approach to correct for the overdispersion noted for these count variables (Tables 3 and 4). Children of low literacy caregivers had greater incidence of ER visits (IRR = 2.05, 95% CI: 1.007, 4.177, P < 0.05) than children of caregivers with adequate literacy, after adjusting for child's sex, age, race, insurance, condition/treatment modality and caregiver's age. Differences in hospitalizations were not significant. Multivariate logistic regressions revealed that caregiver literacy levels were not related to adherence to diets, appointments and medications.

Discussion

Our results indicate that caregivers' functional literacy skills are related to some, but not all, important health outcomes, such as ER utilization, for children seen in our pediatric nephrology practice. We found no significant differences in pediatric patients' adherence behavior by caregiver literacy skills. Adherence to diet, medication and appointments were comparable between

children of caregivers from low versus adequate literacy groups. While adherence outcomes were slightly higher in the more literate group, the differences were not statistically significant. Almost all patients in both functional literacy groups had their prescription medication refilled, followed diets prescribed by the provider and attended medical appointments consistently, regardless of their parents' word reading skills. This is a finding that was somewhat unexpected. Nonadherence is a major concern in pediatric samples, particularly in adolescents with chronic health conditions, with rates averaging ~50–55% across disease regimens [20]. A number of factors affecting adherence have been reported in adults, but research is lacking in understanding the factors that contribute to adherence in children and adolescents with CKD. For this reason, it is difficult to explain what factors account for these comparable adherence rates. Our findings of high adherence across both literacy groups is a favorable outcome, which could suggest that this clinic sample is highly motivated to follow prescribed treatment and the clinic staff is effective at communicating the importance of following treatment recommendations to caregivers of different literacy levels.

We did find significant group differences in ER visits. Children of caregivers with low functional literacy reported significantly more ER visits. We expected to find that children's self-management was compromised as well, but this was not the case in our sample. Expectedly, condition/treatment modality (peritoneal dialysis, transplantation or CKD) was associated with the number of hospitalizations (peritoneal dialysis predicted more hospitalizations, P < 0.05), but not with the incidence of ER visits.

Low functional literacy skills may affect health outcomes in multiple ways. A study examining caregiver literacy effects on

pediatric patient health outcomes found that low caregiver literacy was associated with higher pediatric ER use and more non-urgent visits [21]. Parents with low literacy seek ER care more often and for situations that do not warrant 'urgent' care. It is possible that the symptoms and alterations in health are comparable, but less literate parents are more likely to interpret these situations as 'urgent', and in need of immediate medical attention. In turn, when it comes to hospitalizations, the admission decisions are made by the provider, so parents consult with medical professionals to decide whether hospitalization is necessary; conversely, ER admissions are more easily parent driven in pediatric patient samples.

Condition-specific literacy skills, particularly CKD or ESKD knowledge/understanding and perceived symptom severity, could also represent an important point of discrepancy between caregivers with low versus high literacy. Caregiver literacy predicted asthma-related knowledge, with less literate parents reporting a greater use of rescue medications for their children [14]. Another study, which examined risks and protective factors that contribute to hospital admissions and ER visits among children with complex chronic conditions [22], found that parents' lack of control, frequent worry and uncertainty in caring for the child were major risk factors, while caregivers' knowledge, experience and education were protective factors for these health services. Knowledgeable caregivers react quickly with adequate preventive treatments, promoting better outcomes. While we have no data to describe caregivers' knowledge of CKD/ESKD and its management, these mechanisms likely could be in effect with our sample as well.

In addition, psychological factors, such as self-efficacy, could also play an important role in explaining these findings. A study of disease management self-efficacy in parents of primary school children with asthma found that parents have limited efficacy in more complex management tasks that require higher level judgment and decision making [23]. That study also found that the education level of the parent was associated with asthma management self-efficacy (their belief in their abilities to effectively manage their child's asthma) [23].

Limitations

In our efforts to examine the relationship between caregiver literacy and child health utilization outcomes, there are several limitations that require mention. First, while we used a clinical definition for medication adherence (i.e. medication possession ratios), there is no standard definition in patients with CKD/ESKD. For example, transplant patients need more strict medication adherence (>95%) to achieve better outcomes [18]; however, patients with CKD may be considered adherent at $\geq 80\%$ because the consequences of nonadherence (at least short-term) are less dramatic. Similarly, adherence to diet was determined based on notes by the clinician (registered dietician, nurse or nephrologist) in the medical record, but no standard nutritional evaluation was used. In light of these measurement challenges, replication with more rigorous measures could more adequately address the relationship between caregiver literacy and child health outcomes. Second, we elected to employ a measure of core literacy skills, namely, a standardized word reading task. Although we selected a psychometrically strong measure, it was limited in its assessment of only word reading skills and we did not examine reading comprehension or language comprehension in our definition of literacy. In that sense, our measure of core literacy may have limited our ability to capture people's ability to understand medical information. Perhaps a health literacy measure may have produced different results. Additionally, our operational definition

of literacy (i.e. <7th grade word reading level) may have affected our findings, and defining literacy with a lower grade level cut-point (e.g. 5th grade word reading level) could have created a different set of relationships. While we did not have the sample size to examine alternate grade equivalent cut-points for literacy, this remains an important area for future study.

Implications

Given the findings of this study, we have modified our dialysis training protocols, patient education materials and transplant education sessions to accommodate caregiver and patient literacy levels. Upon admission to our dialysis clinic, we measure caregiver and child literacy level, guiding home dialysis training time for up to 2 weeks (in few cases longer). The CKD education booklet facilitated the development of the 'KIDNOPEDIA™' and our self-management and transition education curriculum 'A.L.L. Y.O.U. N.E.E.D. I.S. L.O.V.E.' are available online at the following website www.med.unc.edu/transition. These tools have been written at the 4th grade literacy level with input from interdisciplinary health providers and educators.

Our goal is to continue improving CKD/ESKD education to be more suitable and universally applicable to patients and their caregivers, in order to lessen the occurrence of unnecessary hospitalizations and nonurgent ER visits. We have also changed our practice by utilizing the 'teach back' method as demonstrated on the following website <http://www.nchealthliteracy.org/teachingaids.html>. Future analysis will need to assess the potential difference in child health outcomes and healthcare utilization before and after the implementation of a carefully devised literacy-based training program.

Conclusions

Patients treated at our pediatric nephrology practice with caregivers who have below 7th grade functional word reading literacy had a greater number of ER visits. While the adherence measures were comparable between the adequate and low literacy groups, caregivers who were less literate tended to have their child seen in the ER more often. Caregivers with lower functional literacy experience more challenges in accurately interpreting symptoms and understanding changes in health. They also have less self-efficacy and tend to overuse the ER. Patient education materials at low literacy levels, along with enhanced health system supports, may help mitigate the relationship between literacy and health outcomes in pediatric patients. Caregivers play such an instrumental role in their children's health management that interventions/health information must be readily accessible and tailored to their functional literacy skills.

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Conflict of interest statement

Results presented in this paper have not been published previously in whole or part, except in abstract format.

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