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Disparities in Health Literacy and Healthcare Utilization among Adolescents and Young Adults with Chronic or End-stage Kidney Disease



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ABSTRACT

Purpose: Low health literacy adversely affects health outcomes in adults with chronic kidney disease. The current study examined associations between limited/inadequate health literacy and health services utilization among adolescents and young adults (AYA) with chronic or end-stage kidney disease (CKD or ESKD).

Design and Methods: This was a retrospective cohort study that enrolled patients from both the pediatric- and adult-focused nephrology clinics of a major university hospital. Demographic information, patients' health literacy and numeracy skills (Newest Vital Sign), and health services utilization (emergency department visits, preventable hospitalizations, total hospitalizations, and length of stay in the hospital) were evaluated. A negative binomial regression model for counts tested the association between AYA patients' literacy/numeracy skills and health services utilization.

Results: The study enrolled 142 participants, 66 (46.5%) patients from adult nephrology and 76 (53.5%) from pediatric nephrology clinics, with a mean age of 20.8 ± 5.60 years (range 12-31). Half of the sample (n=72,51%) had limited health literacy skills. Health literacy/numeracy level was not significantly associated with total hospitalizations, preventable hospitalizations, emergency department (ED) visits, or length of hospital stay. However, public insurance/self-pay, minority race, and kidney transplant/dialysis diagnoses were associated with more preventable hospitalizations.

Conclusions: Among AYA with CKD/ESKD, there were no differences between the low and adequate health literacy groups on health care utilization outcomes when modeling clinical outcomes (total hospitalizations, preventable hospitalizations, ED visits, and length of hospital stay) after adjusting for demographics and disease type. This suggests that other factors warrant consideration in healthcare utilization rates.

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Adolescents and young adults (AYA) with chronic kidney disease (CKD) stages ≥ 2 or end-stage kidney disease (ESKD) have complex treatment plans involving multiple medications along with special food and fluid regimens. To optimize treatment adherence, patients must understand physicians' instructions and properly interpret medication and food labels. This ability to obtain and process basic health information to make appropriate health decisions is called health literacy (Institute of Medicine of the National Academies, 2004).

Low health literacy adversely affects health outcomes (Berkman et al., 2011; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004). The

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estimated prevalence of limited health literacy among older adults with CKD is 23%, and limited health literacy is associated with poor hemodialysis treatment adherence, increased ED visits and increased kidney disease-related hospitalizations (Fraser et al., 2013; Green et al., 2013). Limited health literacy is also linked with low glomerular filtration rate among adults (Devraj et al., 2015). Beyond populations with CKD, adults with poor health literacy have more ED visits, more hospitalizations, higher hospital reutilization 30 days after discharge, higher health care costs, and poorer overall health status compared to those with adequate literacy (Herndon, Chaney, & Carden, 2011; Mitchell, Sadikova, Jack, & Paasche-Orlow, 2012). In contrast to the wealth of knowledge available on older adults, AYA have received less attention in health literacy research, including patients with CKD or ESKD.

AYA patients with CKD or ESKD are at greater risk for poor adherence to treatment regimens, poor attendance at clinic visits, and

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increased preventable hospitalizations during the 3–4 years following transition from pediatric to adult care (Dobbels, Van Damme-Lombaert, Vanhaecke, & De Geest, 2005; Samuel et al., 2014; Watson, 2000). Limited health literacy is associated with these outcomes in adult populations, so the current study hypothesized that a similar relationship might exist among AYAs. The purpose of this study was to examine the role of health literacy/numeracy as a potential predictor of ED visits, preventable hospitalizations, total hospitalizations, and length of hospital stay among AYA with CKD/ESKD. The hypothesis was that poor health literacy/numeracy skills would be associated with poor health outcomes in this population.

Methods

Participants

The study recruited AYA with CKD or ESKD from either pediatric or adult nephrology clinics at the University of North Carolina Hospitals in the Southeast USA between January and December 2012. Patients ages 12–31 with ESKD or CKD stages ≥2 were eligible for recruitment. Patients with primary or secondary renal disease (i.e., systemic lupus erythematosus), transplant or dialysis were eligible to participate. CKD stage was determined using an age-appropriate estimation of glomerular filtration rate (Warady et al., 2015). Additional eligibility criteria included English fluency and adequate cognitive abilities as determined by their healthcare providers. The study was described to all eligible participants and if they agreed to participate, informed consent and assent forms (when appropriate) were obtained. The protocol was approved through the University of North Carolina Institutional Review Board.

Measures

Socio-demographic Variables

The study collected socio-demographic and clinical variables which were extracted from the electronic medical record. These variables included age, race, sex, type of insurance and primary diagnosis. Percentage of life with the disease was calculated by dividing the age at first presentation to the hospital or clinic with renal diagnosis by the participant's age at the time of data collection in July 2014. This variable was included to account for the fact that the data that was not able to capture all ED visits or hospitalizations prior to patients' initial presentations and enrollments in the electronic medical record.

Health Literacy/Numeracy

Health literacy and numeracy was measured using Newest Vital Signs (NVS), a six-item screening instrument (Weiss et al., 2005). The NVS is verbally administered, and the questions evaluate the ability to understand and use information presented on a standardized Nutrition Facts label (i.e., an ice cream container). The ability to answer the questions correctly parallels the skills needed to understand the majority of health-related instructions (Weiss et al., 2005). The instrument has been used in patients over the age of seven (Warsh, Chari, Badaczewski, Hossain, & Sharif, 2014). Scores range between 0 and 6 and are transformed into categories reflecting the likelihood of adequate health literacy based on the gold-standard Test of Functional Health Literacy in Adults (TOFHLA): NVS score < 4 is 100% sensitive, 64% specific for predicting inadequate or marginal range health literacy, where individuals would likely require assistance to completely understand instructions for their medical care. All individuals with NVS score > 4 will have adequate health literacy when measured by TOFHLA. Individuals with NVS score < 2 represent a particularly high-risk group because they have a >50% chance or marginal or inadequate literacy skills (Weiss et al., 2005).

Data was analyzed using both the three-group categorization (NVS score < 2, 2-3, and ≥ 4) and then collapsed into two groups, one with a

high likelihood of limited literacy (NVS score < 4) and the second with a high likelihood of adequate literacy (NVS score \ge 4). Consequently, the regression analysis results are reported using just the two groups of adequate and inadequate health literacy.

Healthcare Services Utilization

Healthcare services were quantified using a number of different measures, including ED visits, total hospitalizations, preventable hospitalizations, and total inpatient days. These variables were obtained through a review of the electronic medical record (available since 1984), and counts included all incidents - counts of hospitalizations, preventable hospitalizations (Samuel et al., 2014), ED visits, and numbers of days spent in the hospital - from patients' initial presentations to the main hospital or affiliated outpatient clinic through July 2014. Discharge diagnoses were used to categorize hospitalizations as preventable or not. When discharge diagnoses were unavailable and/or a discrepancy existed between the documented admitting and discharge diagnoses, the research team's senior pediatric nephrologist was consulted. The categorization of avoidable hospitalizations developed by Samuel et al. in 2014 specifically for a population of pediatric and young adult patients with ESKD was adopted for this paper. In that categorization, a modified Delphi process was used to elicit expert responses to the question, "could high-quality ambulatory care have avoided the need for a hospitalization?" for each of the ESKD-relevant diagnoses considered. Examples of avoidable hospitalization diagnoses included in the final criteria are hyperkalemia, urinary tract infections, secondary hypertension, fluid overload and transplant rejection episodes (Samuel et al., 2014).

The total number of inpatient days were calculated based on the number of days listed from admission to discharge for each admission to the hospital prior to July 2014. Half of the sample (n = 71) of patient charts were reviewed by a second reviewer for internal consistency.

Data Analyses

Univariate statistical methods were employed to describe the sample, explore distributional properties of the outcomes and test for differences in literacy skills by sociodemographic characteristics. *t*-tests were used to determine if continuous measures (age and percent of life with disease) differed by dichotomized health literacy group, while chisquare tests were employed to test categorical variables (race, sex, insurance type, and diagnosis) using health literacy as the grouping variable. To test the relationship of health literacy and outcomes, controlling for disease type and basic demographics, multiple regression methods for count outcomes were employed (Cameron & Trivedi, 2013; Hilbe, 2014; Long, 1997). Due to overdispersion of healthcare utilization outcomes, multiple separate negative binomial regressions were employed using SAS ® 9.4 software (SAS Institute, Cary, NC, USA).

Results

Patient Characteristics

The study enrolled 142 participants from the pediatric (n = 66; 46.5%) and adult (n = 76; 53.5%) nephrology clinics at a large university hospital's Kidney Center in the Southeast. They had either public (45.1%) or private insurance (44.4%), and the majority of participants were females (62.7%). In terms of race, 62 were White, 57 were African-American, and 23 were classified as "other race." The mean age of participants was 20.8 ± 5.60 years (range 12–31 years), and the mean percentage of life with disease was 59.7 ± 35.7 (range 0–100%). A dichotomous variable was created for age to separate and compare pediatric and adult patients, with a cutoff at 18 years of age (younger than 18 representing pediatric patients [n = 49], and 18 or older as adult patients [n = 93]). Participant primary conditions included CKD stages 2–4 (n = 56), systemic lupus erythematosus (n = 26), kidney

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