

Prevalence and Demographic and Clinical Associations of Health Literacy in Patients on Maintenance Hemodialysis

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Summary

Background and objectives Although limited health literacy is estimated to affect over 90 million Americans and is recognized as an important public health concern, there have been few studies examining this issue in patients with chronic kidney disease. We sought to characterize the prevalence of and associations of demographic and clinical characteristics with limited health literacy in patients receiving maintenance hemodialysis.

Design, setting, participants, & measurements As part of a prospective clinical trial of symptom management strategies in 288 patients treated with chronic hemodialysis, we assessed health literacy using the Rapid Estimate of Adult Literacy in Medicine (REALM). We defined limited health literacy as a REALM score ≤ 60 and evaluated independent associations of demographic and baseline clinical characteristics with limited health literacy using multivariable logistic regression.

Results Of the 260 patients who completed the REALM, 41 demonstrated limited health literacy. African-American race, lower educational level, and veteran status were independently associated with limited health literacy. There was no association of limited health literacy with age, gender, serologic values, dialysis adequacy, overall symptom burden, quality of life, or depression.

Conclusions Limited health literacy is common among patients receiving chronic hemodialysis. African-American race and socioeconomic factors are strong independent predictors of limited health literacy. These findings can help inform the design and implementation of interventions to improve health literacy in the hemodialysis population.

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Introduction

Health literacy is the ability to obtain, process, and understand health information to make appropriate health decisions (1). Limited health literacy is estimated to affect over 90 million Americans and is now recognized as an important public health concern (2). Patients with limited health literacy may have difficulty understanding written medical information, communicating with healthcare providers, and navigating the increasingly complex healthcare system. Studies in various patient populations demonstrate an association of limited health literacy with poorer health-related knowledge (3,4), lower use of preventive health services (5,6), increased risk of hospitalization (7,8), decreased medication adherence (9,10), greater probability of depressive symptoms (11,12), poorer health status (13,14), higher healthcare costs (15,16), and increased mortality (17,18). In addition, there is evidence that limited health literacy contributes to racial disparities in health outcomes (19–21).

Promising interventions to mitigate the effects of low health literacy include intensive disease or self-management programs, which have been shown to be effective in decreasing disease severity, improving self-management behaviors, and reducing hospitalizations (22–24).

Despite this knowledge, few studies have examined health literacy in patients with ESRD. Health literacy may be particularly germane to the care and outcome of patients with ESRD receiving hemodialysis, because this patient population must attend regular dialysis treatments to maintain electrolyte and fluid balance; follow dietary restrictions related to fluid, sodium, phosphorous, and potassium intake; and adhere to multiple medications to treat or prevent the complications of ESRD. Preliminary studies suggest that limited health literacy is prevalent in patients receiving chronic hemodialysis and may be associated with adverse outcomes including mortality (25,26). However, these studies either enrolled small numbers

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of patients or restricted their study populations to those suspected of having low health literacy. We sought to build upon past studies by characterizing health literacy in a broader population of patients, including those receiving care in Veterans Affairs, academic, and private practice-affiliated dialysis settings and assessing the associations of demographic and clinical characteristics, including health-related quality of life, symptom burden, and depression, with limited health literacy.

Materials and Methods

Patient Population

Subjects included in this analysis were enrolled in the SMILE study, a multicenter randomized clinical trial comparing symptom management strategies in patients treated with chronic hemodialysis (27). Study personnel recruited patients from nine outpatient dialysis units in and around Pittsburgh, Pennsylvania between January 2009 and January 2010. These dialysis units were staffed by academic and private nephrologists, nurse practitioners, and physician assistants. Eligible patients were older than 17 years of age, spoke English, and were receiving outpatient in-center hemodialysis. Patients undergoing active work-up for living donor kidney transplant and/or considering transfer to peritoneal dialysis at the time of recruitment were excluded to help ensure that the study population would remain on chronic hemodialysis for the duration of the parent trial. As part of screening, we assessed cognitive function using the mini-Cog, a three-item test of cognitive function (28). We excluded patients with scores <3 , which is consistent with cognitive impairment. We enrolled all patients who met the eligibility criteria and consented to participate. The study was approved by the institutional review boards of the University of Pittsburgh, the Veterans Administration Pittsburgh Healthcare System, and the Western Institutional Review Board.

Data Collection

We assessed patient demographic characteristics including self-reported race and ethnicity, age, sex, educational level, veteran status, and annual income by conducting patient interviews. We evaluated baseline clinical characteristics including dialysis vintage, history of past renal transplant, type of vascular access, and comorbid illness burden on the basis of the Charlson Comorbidity Index by reviewing the dialysis charts. We also abstracted the most recent laboratory values (*i.e.* hemoglobin; serum calcium, phosphorous, albumin, and intact parathyroid hormone concentrations; and Kt/V and urea reduction ratio) at the time of the first study assessment. We assessed baseline health-related quality of life, depression, and overall symptom burden using the Short Form 12, Patient Health Questionnaire 9, and Dialysis Symptom Index, respectively (29–34).

Assessment of Health Literacy

After enrollment, research personnel assessed study participants' visual capacity by asking them to read a series of numbers typed at 14-, 20-, and 30-point-sized font. Patients unable to read all of the numbers written at 14-point font were offered reading glasses to complete the health literacy

assessment. After this assessment of visual capacity, study personnel assessed patients' health literacy using the Rapid Estimate of Adult Literacy in Medicine (REALM), a 66-item word recognition tool that has been validated against general measures of literacy (35) and other health literacy tools (36,37). This instrument takes 2 to 3 minutes to administer and is designed to assess an adult patient's ability to read common medical words and lay terms for body parts and illnesses. REALM scores range from 0 to 66, with scores of 0 to 18 representing a reading level of third grade or less ("may not be able to read most low literacy materials and may need repeat oral instructions"); 19 to 44 representing a fourth to sixth grade reading level ("may need low literacy materials and may not be able to read prescription instructions"); 45 to 60 representing a seventh to eighth grade reading level ("may struggle with most currently available patient education materials"); and >60 representing a ninth grade reading level or above ("should be able to read most patient education materials") (35). Prior studies have defined limited health literacy as REALM scores ≤ 60 (18,26). We used this threshold to define limited health literacy in our study participants.

Statistical Analyses

We described baseline demographic and clinical characteristics using proportions for discrete characteristics and, because of skewed distributions, medians and interquartile ranges for continuous variables. Univariate associations of demographic characteristics (*e.g.* age, sex, and race) and clinical variables (*e.g.* dialysis vintage and serologic values) with limited health literacy were assessed using Wilcoxon rank sum test for continuous variables, Fisher's exact tests for dichotomous and nominal variables, and Cochran-Mantel-Haenszel tests of trend for ordinal characteristics. Demographic and clinical factors associated with limited health literacy on the basis of two-tailed P values <0.10 in univariate analyses were included in a random effects multivariable logistic regression model to assess the independent association of these variables with limited health literacy while accounting for the nonindependence of patients treated at the same dialysis unit. We used multiple imputation to adjust for nonresponse to patient income (38). Statistical significance was denoted by a two-tailed P value of <0.05 . All of the analyses were conducted using SAS 9.2 (Cary, NC) and Stata 11.0 (College Station, TX).

Results

Study Population

We screened 439 patients for the parent clinical trial, of whom 85 (19%) declined to participate and 39 (9%) were excluded on the basis of established criteria. Of the 315 patients who initially consented to participate, 27 (9%) withdrew, underwent renal transplantation, transferred to a nonparticipating dialysis unit, or died before data collection, resulting in a final trial population of 288 participants (Figure 1). Twenty-eight patients (10%) refused to complete the REALM, 22 (79%) of whom reported the reason for refusal to be related to problems with their vision. Two hundred sixty (90%) of the enrolled participants completed the REALM. Their median age was 64 years, 57% were male, and 40% were African American (Table 1). Com-

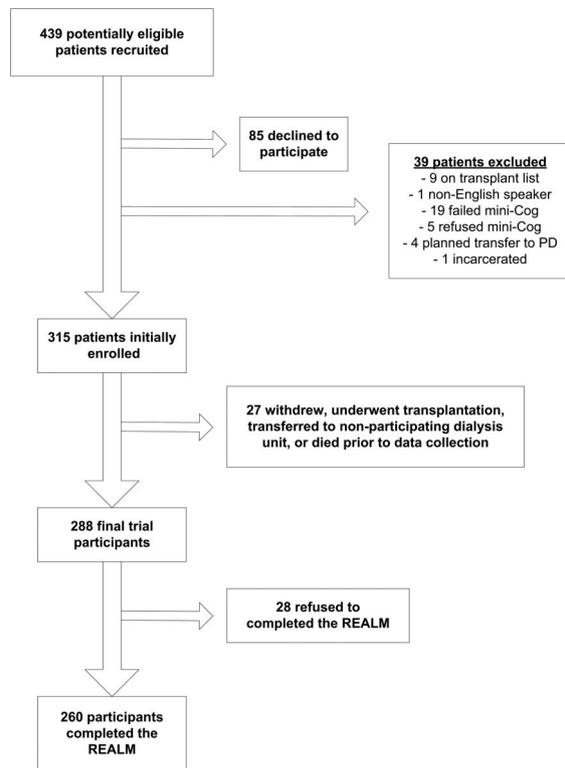


Figure 1. | Study population. PD, peritoneal dialysis.

pared with participants who completed the REALM, patients who refused the REALM were more likely to have a lower than high school level of education (odds ratio [OR] = 3.5; 95% confidence interval [CI], 1.3 to 8.9).

Health Literacy Scores

Overall, 41 of 260 patients (16%) who completed the REALM demonstrated scores on this instrument of ≤ 60 , indicating the presence of limited health literacy. The prevalence of limited health literacy ranged from 7% to 37% at the nine participating dialysis units. Of the 41 patients with limited health literacy, 34 (83%) had REALM scores of 45 to 60 (*i.e.* seventh to eighth grade reading level), six (15%) had scores of 19 to 44 (*i.e.* fourth to sixth grade reading level), and one (2%) had a score < 19 (*i.e.* less than a fourth grade reading level). Twenty-seven of the 41 (66%) patients with limited health literacy reported a high school equivalent or higher level of education. Conversely, 17 (8%) of 219 patients with adequate literacy (REALM scores > 60) reported a less than high school level of education.

Factors Associated with Limited Health Literacy

In unadjusted analyses, demographic factors associated with limited health literacy included African-American race, lower educational attainment, lower income, and veteran status (Table 1). Patients with higher burdens of comorbid illness and those dialyzing with an arteriovenous fistula or graft (as compared with a catheter) were also more likely to demonstrate limited health literacy; however, additional analyses suggested that these associations were driven by educational status and study site, respectively (data not shown). There were no associations of age;

gender; or markers of quality of care including hemoglobin level, serum phosphorus, and intact parathyroid hormone level or dialysis adequacy with limited health literacy. Although there was a trend for patients with limited health literacy to be more depressed than patients with adequate health literacy, these differences did not meet the level of statistical significance in unadjusted analyses (Table 1). Quality of life and overall symptom burden were similar in patients with and without limited health literacy.

In multivariable analyses, African-American race (adjusted OR = 3.01; 95% CI, 1.40 to 6.49), lower educational attainment (less than high school: OR = 12.1 and 95% CI, 4.10 to 35.7; high school equivalent: OR = 3.70 and 95% CI 1.46 to 9.36), and veteran status (adjusted OR = 3.68; 95% CI, 1.61 to 8.43) were independently associated with limited health literacy (Table 2). Veterans receiving dialysis within and outside the Veterans Affairs healthcare system were more likely to have limited health literacy than non-veterans after adjusting for potential confounders. Finally, limited health literacy was not an independent predictor of type of vascular access or Charlson Comorbidity Index score.

Discussion

In this cross-sectional analysis of patients receiving chronic hemodialysis, we found that limited health literacy is reasonably common and is independently associated with African-American race, lower educational level, and veteran status. However, some patients with higher educational levels also demonstrated limited health literacy. These observations build upon prior reports of health literacy in this patient population and have important clinical and research implications.

The prevalence of limited health literacy in our study is approximately 50% lower than has been reported in prior studies of patients on hemodialysis (25,26). The use of different health literacy assessment tools and criteria for enrollment as well as nonresponse bias may account for these differences. Grubbs *et al.* (25) administered the Short Test of Functional Health Literacy in Adults (S-TOFHLA) to 62 patients on chronic hemodialysis and reported a prevalence of limited health literacy of 32%. Unlike the REALM, which measures recognition and pronunciation of common medical words, the S-TOFHLA measures numeracy and reading comprehension. Although both instruments have been shown to be highly correlated ($r = 0.80$) in the general population (37), it is unclear which instrument is a more reliable and valid tool in patients on chronic hemodialysis. Cavanaugh *et al.* (26) used the REALM to assess health literacy in 480 incident hemodialysis patients and reported a prevalence of limited health literacy of 32%. However, this study was restricted to patients suspected, *a priori*, of having limited health literacy, which may have accounted for the higher prevalence than demonstrated in our study. Nonresponse bias may also account for the lower prevalence of limited health literacy in our study. Patients in our study who refused to complete the REALM were more likely to have lower educational attainment, which was independently associated with limited health literacy. Past studies have found that accounting for nonresponse bias increases the estimated prevalence of limited

Table 1. Comparison of demographic and clinical characteristics by REALM score

Variable	Overall Population (n = 288)	REALM Score ≤60 (n = 41)	REALM Score >60 (n = 219)	P ^a
Demographic variables				
median age: years	64.0 (56 to 73)	61 (57 to 73)	63 (55 to 73)	0.76
gender: male	163 (57%)	27 (66%)	123 (56%)	0.3
race: African American	114 (40%)	24 (59%)	79 (36%)	<0.01
ethnicity: Hispanic	8 (3%)	1 (2%)	6 (3%)	1.00
Education				
less than high school	40 (14%)	14 (34%)	17 (8%)	<0.01
high school equivalent	92 (32%)	17 (42%)	64 (29%)	
more than high school	154 (54%)	10 (24%)	136 (63%)	
Income				
less than \$30,000/year	144 (50%)	22 (54%)	105 (48%)	<0.01
at least \$30,000/year	91 (32%)	6 (15%)	80 (37%)	
unknown	52 (18%)	13 (32%)	33 (15%)	
Veteran	86 (30%)	18 (44%)	60 (28%)	0.04
Married	126 (44%)	14 (34%)	101 (46%)	0.17
Dialysis/clinical variables				
Dialysis vintage: years	2.3 (1.0 to 4.4)	2.4 (1.0 to 4.1)	2.2 (0.8 to 4.7)	0.82
Dialysis adequacy: Kt/V	1.5 (1.4 to 1.6)	1.5 (1.4 to 1.7)	1.5 (1.4 to 1.6)	0.94
Dialysis access				
Catheter	59 (20%)	3 (7%)	51 (23%)	0.02
AV fistula or graft	228 (79%)	38 (93%)	167 (77%)	
CCI score				
1 to 2	64 (23%)	6 (15%)	57 (27%)	0.02
3 to 4	109 (39%)	13 (32%)	83 (39%)	
>5	110 (39%)	22 (54%)	75 (35%)	
Laboratory values				
hemoglobin (g/dl)	11.6 (10.9 to 12.2)	11.9 (11.2 to 12.3)	11.6 (10.9 to 12.2)	0.18
albumin (g/dl)	3.8 (3.6 to 4.1)	3.7 (3.5 to 4.1)	3.8 (3.6 to 4.1)	0.65
calcium (mg/dl)	8.9 (8.5 to 9.3)	8.8 (8.5 to 9.1)	8.9 (8.5 to 9.3)	0.28
phosphorous (mg/dl)	5.0 (4.4 to 5.9)	5.1 (4.1 to 6.9)	5.0 (4.3 to 5.9)	0.40
iPTH (pg/ml)	253 (175 to 397)	266 (189 to 383)	244 (165 to 386)	0.55
Health-related variables				
Symptom burden ^b	12.0 (7.0 to 17.0)	12.5 (8.0 to 17.0)	12.0 (7.0 to 17.0)	0.86
Quality of life ^c	7.0 (5.0 to 8.0)	7.0 (5.0 to 8.5)	7.0 (5.0 to 8.0)	0.93
mental health	50.4 (40.2 to 58.2)	48.0 (36.7 to 61.5)	50.1 (41.9 to 57.5)	0.96
physical health	35.3 (27.0 to 44.2)	32.8 (26.9 to 38.6)	36.6 (27.1 to 44.9)	0.22
depression ^d	72 (25%)	14 (34%)	50 (23%)	0.17

Category percentages may not equal 100% because of rounding. REALM, Rapid Estimate of Adult Literacy in Medicine; AV, arteriovenous; CCI, Charlson Comorbidity Index; iPTH, intact parathyroid hormone.

^aComparison of patients with REALM ≤60 and >60.

^bNumber of symptoms reported on the Dialysis Symptom Index.

^cScores on Short Form 12.

^dProportion of patients with Patient Health Questionnaire 9 score of ≥10.

Table 2. Factors independently associated with limited health literacy

Variable	Unadjusted OR (95% CI)	Adjusted OR (95% CI) ^a
African-American race	2.50 (1.27 to 4.94)	3.01 (1.40 to 6.49)
Education^b		
less than high school	12.1 (4.43 to 32.9)	12.1 (4.10 to 35.7)
high school equivalent	3.75 (1.60 to 8.79)	3.70 (1.46 to 9.36)
Income^c		
less than \$30,000/year	2.56 (1.01 to 6.49)	1.52 (0.51 to 4.57)
Veteran	2.06 (1.04 to 4.09)	3.68 (1.61 to 8.43)

OR, odds ratio; CI, confidence interval.

^aIndependent odds of limited health literacy.

^bReferent category is more than a high school level of education.

^cReferent category is income at least \$30,000/year.

health literacy (39). Additional research is needed to determine the precise prevalence of limited health literacy in the overall population of patients on chronic hemodialysis.

Even if the prevalence of limited health literacy in patients on chronic hemodialysis is 16% as seen in our study, the number of patients receiving chronic hemodialysis in the United States affected by this problem would be greater than 56,000 (40). This observation is notable given the potential importance of written materials and verbal instructions to this patient population. Past research demonstrated that patients on hemodialysis take an average of 19 medications each day, and approximately 25% of patients consume more than 25 medications on a daily basis (41). Adequate health literacy may be important for patients to be able to adhere to such medication regimens as cited in a recent comprehensive review by Browne and Merighi (42). Moreover, a study by Manley *et al.* (43) documented that medication-related problems, including adverse drug reactions, overdosing, and underdosing, were very common in ambulatory hemodialysis patients. Whether and how limited health literacy contributes to such medication-related problems was not investigated. Many patients on chronic hemodialysis are also counseled on the importance of diet and are provided with written materials instructing them to follow diets that are low in salt, potassium, and phosphorus. Although our study did not find differences in the serum phosphorus concentration on the basis of patients' health literacy level, our assessment of this serologic parameter was cross-sectional rather than longitudinal. Nonetheless, it seems quite plausible that limited health literacy could affect patients' capacity to adhere to dietary restrictions. Efforts to understand whether and how limited health literacy impacts long-term adherence to increasingly complex medication regimens and dietary restrictions are clearly needed because dietary and treatment adherence could be directly impacted by interventions to improve health literacy.

Although we and others have demonstrated an independent association of lower educational attainment with limited health literacy, we found that a notable proportion of patients with limited health literacy reported a high school equivalent or higher level of education. This may reflect the observation that the assessment of educational level in studies such as ours is based on quantifying the years of school completed, not the reading skills obtained or their permanency. Studies in other populations have shown that the last grade completed in school is a poor indicator of reading ability (44). In light of this observation, it may not be appropriate for renal providers to guess or try to predict which patients have limited health literacy on the basis of educational attainment. Rather, as has been advocated by the Agency for Healthcare Research and Quality, the federal agency that aims to enhance the safety and effectiveness of health care, renal providers should consider adopting a "health literacy universal precautions" approach to evaluating this problem (45).

Our finding that African-American race and veteran status are each independently associated with limited health literacy is consistent with previous studies (46,47). Although we did not investigate the factors mediating these associations, this finding may reflect underlying differences in the quality of education, cultural variability in

understanding health-related terminology, and/or differences in exposure to the healthcare system. Nonetheless, African-Americans with chronic kidney disease are less likely to be seen by a nephrologist, more likely to progress to ESRD, and less likely to be listed for or receive a renal transplant (48). Moreover, there is evidence from studies in patients with other chronic diseases that health literacy mediates racial disparities in health outcomes (49,50). This suggests that efforts to improve health literacy among racial minorities and sociodemographically disadvantaged patients, including veterans, with chronic renal disease and ESRD may be a means to reduce health disparities and improve outcomes. Such efforts will need to consider the cultural, racial, and sociodemographic characteristics of the patients most likely to potentially derive benefit from such interventions.

Our study has several limitations. First, although this represents one of the largest studies of health literacy in patients on chronic hemodialysis, our sample size was relatively small. Second, we excluded patients being worked up for living renal transplant or considering transfer to peritoneal dialysis. Exclusion of such subjects, who may have higher health literacy, could impact the generalizability of our prevalence estimate of limited health literacy. Furthermore, our study involved patients participating in a randomized clinical trial, so our results may not be generalizable to the overall dialysis population. Rather, our findings may be most generalizable to dialysis patients who participate in clinical trials. Third, although the REALM is a widely used measure of health literacy that assesses reading and pronunciation of medical terms, it does not capture other skills that may be important including numeracy, oral communication, and memory. Fourth, there were few Hispanics or other ethnic minorities other than African Americans in our study population, which limits the external validity of our findings to such patient groups. Fifth, our assessment of visual capacity has not been previously validated, and therefore our findings in this regard may not be accurate or generalizable. Finally, although other studies suggest that limited health literacy is associated with a lower likelihood of referral for renal transplantation and a higher likelihood of mortality (25,26), we did not assess the associations of limited health literacy with downstream, patient-centered outcomes.

In conclusion, we found that limited health literacy is quite common among hemodialysis patients and is most likely to be present in African Americans, those with lower levels of educational attainment, and veterans. Further studies are needed to assess the health implications of limited health literacy in patients on hemodialysis including whether limited health literacy is associated with patient knowledge, self-management behaviors, and access to care and how this impacts health disparities and longer-term outcomes. A broader understanding of these relationships will facilitate the development of targeted interventions to improve health literacy, quality of care, and outcomes in patients with kidney disease.

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Disclosures

None.

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MANY DIALYSIS PATIENTS MAY NOT UNDERSTAND IMPORTANT HEALTH INFORMATION

Improving Health Literacy Could Benefit Patients

Washington, DC (April 28, 2011) — Many patients on dialysis may not understand medical information critical to their wellbeing, according to a study appearing in an upcoming issue of the *Clinical Journal of the American Society Nephrology* (CJASN). The results suggest that clinicians must understand and address the limited health literacy of patients with kidney disease.

Patients with limited health literacy—the ability to obtain, process, and understand health information in order to make appropriate health decisions—may not fully understand written medical information, may not be able to communicate effectively with healthcare providers, or navigate the increasingly complex healthcare system. Studies suggest that limited health literacy may negatively affect patients' wellbeing and increase healthcare costs.

Health literacy is particularly important for kidney patients undergoing dialysis. They must attend treatment sessions several days a week, follow dietary and fluid restrictions, and adhere to complex medication regimens, all of which require patients to understand and act on complicated health-related information. Jamie Green, MD (University of Pittsburgh) and her colleagues tested 260 patients on long-term dialysis with a tool that assesses one's ability to read common medical words and lay terms for body parts and illnesses.

The investigators found that 16% of the patients on dialysis (41 of the 260 patients) had limited health literacy. There are currently more than 350,000 patients in the United States on dialysis, so this represents a significant number of individuals who could benefit from being better able to understand and manage their kidney health. While limited health literacy was present in all subgroups of patients, those with lower educational levels, African Americans, and veterans were less likely to effectively obtain and process relevant health information.

Patients with less than a high school education exhibited more than a 12-fold increased risk of low health literacy, and African Americans and veterans had more than a 3-fold increased risk of having limited health literacy. The researchers are currently following these individuals to determine if limited health literacy affects how patients adhere to dialysis treatment, whether they undergo kidney transplantation, and whether they die prematurely.

“We anticipate our findings will increase awareness of the importance of health literacy in patients with kidney disease, stimulate providers to consider literacy when communicating with patients, and lead to future studies to address limitations in health literacy,” said Green.

Study co-authors include Maria Mor, PhD, Mary Ann Sevick, Paul Palevsky, MD, Michael Fine, MD, Steven Weisbord, MD (VA Pittsburgh Healthcare System and University of Pittsburgh); Anne Marie Shields (VA Pittsburgh Healthcare System); and Robert Arnold, MD (University of Pittsburgh).

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The article, entitled “Prevalence and Demographic and Clinical Associations of Health Literacy in Patients on Maintenance Hemodialysis” will appear online at <http://cjasn.asnjournals.org/> on May 5, 2011, doi 10.2215/CJN.09761110.

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Founded in 1966, and with more than 12,000 members, the American Society of Nephrology (ASN) leads the fight against kidney disease by educating health professionals, sharing new knowledge, advancing research, and advocating the highest quality care for patients.

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