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Association of Health Literacy and Numeracy With Lupus Knowledge and the Creation of the Lupus Knowledge Assessment Test

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ABSTRACT. ***Objective.*** Limited health literacy and numeracy are associated with worse patient-reported outcomes and higher disease activity in systemic lupus erythematosus (SLE), but which factors may mediate this association is unknown. We sought to determine the association of health literacy and numeracy with SLE knowledge.

Methods. Patients with SLE were recruited from an academic center clinic. Participants completed validated assessments of health literacy (Newest Vital Sign [NVS]; n = 96) and numeracy (Numeracy Understanding in Medicine Instrument, Short Version [S-NUMI]; n = 85). They also completed the Lupus Knowledge Assessment Test (LKAT), which consists of 4 questions assessing SLE knowledge that were determined through consensus expert opinion for their wide applicability and importance related to self-management of the disease. Descriptive statistics and multivariable logistic regression modeling were used to analyze the results.

Results. In our SLE cohort (n = 125), 33% (32/96) had limited health literacy and 76% (65/85) had limited numeracy. The majority correctly identified that hydroxychloroquine prevented SLE flares (91%); however, only 23% of participants correctly answered a numeracy question assessing which urine protein to creatinine (UPC) ratio was > 1000 mg/g. The mean LKAT score was 2.7 out of 4.0. Limited health literacy, but not numeracy, was associated with lower knowledge about SLE as measured by the LKAT, even after adjusting for education.

Conclusion. Patients with SLE with limited health literacy had lower knowledge about SLE. The LKAT could be further refined and/or used as a screening tool to identify patients with knowledge gaps. Further work is needed to improve patients' understanding of proteinuria and investigate whether literacy-sensitive education can improve care.

Key Indexing Terms: systemic lupus erythematosus, health literacy, health numeracy, lupus knowledge, patient education

A high degree of health literacy is required to effectively manage systemic lupus erythematosus (SLE), a chronic, multi-organ disease with complicated medical therapies. Health literacy involves obtaining, communicating, processing, and understanding basic health information and the services needed to make appropriate health decisions.[1] A component of health literacy is called numeracy, which involves quantitative math skills required to complete numerical tasks in health care, such

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as calculating medication dosages.[1] Patients with SLE who lack knowledge about their disease may make less informed health decisions, which can have subsequent adverse clinical consequences and outcomes. Difficulty understanding complex medication regimens with nuanced side effects may contribute to nonadherence. For example, a patient with lupus nephritis (LN) receives care from multiple specialists, needs frequent laboratory monitoring, is prescribed upwards of 6 multidose medications, and is at risk for permanent kidney failure if unable to adhere to these complicated regimens. Given the intricacies of managing SLE, adequate knowledge of disease and related health literacy is critical for self-efficacy and optimal disease management.

Limited health literacy has been associated with worse clinical outcomes in multiple chronic diseases.[2–8] For example, in diabetes and hypertension, limited patient knowledge about their disease or chronic condition is associated with low health literacy and postulated as one of the causes for poorer clinical outcomes in these patients[3,9,10] While previous work has demonstrated that limited health literacy and numeracy is associated with worse patient-reported outcomes and higher disease activity in SLE,[11,12] no studies have examined the relationship between health literacy and SLE knowledge. Further, while several self-administered questionnaires have been developed to assess patient knowledge across chronic diseases such as diabetes, HIV, and asthma,[13,14,15] as well as for osteoarthritis and reproductive health for women with rheumatic diseases,[16,17] no SLE-specific knowledge assessments have been developed, to our knowledge. Identifying lapses in SLE knowledge is critical to bridge the gaps in disease understanding and self-management among vulnerable patients with SLE. We hypothesize that health literacy level affects the skills needed to understand and evaluate health-related information; therefore, patients with low health literacy and numeracy would have less knowledge about SLE.

METHODS

Study design. This study was a cross-sectional study performed from March 2019 to December 2020 within an academic SLE clinic. All patients gave written informed consent to participate in a prospective SLE registry (Duke University Institutional Review Board [IRB] Pro00094645) and provided verbal consent to complete the additional health literacy and numeracy tests (IRB Pro00094645, Specific Aim 2). All eligible patients were approached, with > 90% agreeing to participate. Eligible patients were aged ≥ 18 years and had a diagnosis of SLE by the 1997 American College of Rheumatology or 2012 Systemic Lupus International Collaborating Clinics SLE classification criteria.[18,19] Patients were excluded from participation if unable to speak or read English (an exclusion criteria for the Duke Lupus Registry [DLR]), if they declined, or if they were too ill to participate on the day of the visit as determined by the provider.

Demographics. Sociodemographic characteristics including patient age, gender, race, ethnicity, education, employment status, insurance type, disability status (self-reported by patient as "on disability"), and annual income were self-reported by paper survey upon enrollment into the DLR (Table 1).

Disease activity. The Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) and physician global assessment (PGA) measures were determined by the physician at each visit.[20,21] Active LN at the visit was defined as proteinuria, hematuria, pyuria, or urinary casts due to SLE.[22] History of LN and SLE disease duration were obtained by chart review from a rheumatologist (JLR).[23,24]

Lupus Knowledge Assessment Test. Six rheumatologists from our tertiary center SLE clinic developed 28 questions to identify gaps in patient knowledge as part of a quality improvement project (Supplementary Material, available from the authors on request). The questions were narrowed down to 4 through consensus discussion, selecting topics that were discussed frequently at visits and would be applicable for most patients with SLE. This 4-item questionnaire was named the Lupus Knowledge Assessment Test (LKAT; Table 2). Questions were adapted to SLE based on measures addressing similar concepts in other chronic diseases; for instance, identification of a blood sugar level within a normal glucose range was translated, on a conceptual level, to identifying which urine protein to creatinine (UPC) ratio was abnormal or > 1000 mg/g.[25,26] Items were written at a 6th-grade reading level or below, as determined by the Flesch-Kincaid Grade Level (5.6 when excluding hydroxychloroquine [HCQ] drug names). The LKAT was calculated by tabulating the number of correct responses into a cumulative LKAT score from 0 to 4.

Health literacy. We measured health literacy using the validated Newest Vital Sign (NVS).[27] The NVS asks the patient to read and interpret a nutrition label, and includes questions assessing reading comprehension, nutrition label interpretation, and numeracy skills. The NVS is scored from 0 to 6; patients with an NVS < 4 have low health literacy and those with an NVS ≥ 4 have adequate health literacy.[27] In our study, the questions were read aloud by a test administrator (MM), who administered all in-person NVS assessments. A small proportion of NVS (n = 18) were administered by virtual platform (Zoom; https://zoom.us) by 3 investigators (MM, ACB, CH), due to the coronavirus disease 2019 (COVID-19) pandemic.

Health numeracy. We measured the specific domain of health numeracy with the validated Numeracy Understanding in Medicine Instrument, Short Version (S-NUMI).[26] The S-NUMI is an 8-question measure that assesses mathematical calculations in health-related tasks, such as identifying a normal blood glucose level within range or determining the probabilities of specific side effects. Patients read the multiple-choice math questions and complete the assessment on paper, which are then scored by number of correct responses. Scores range from 0 to 8; patients with an S-NUMI < 7 were deemed to have inadequate numeracy and those with an S-NUMI ≥ 7 were deemed to have adequate numeracy as previously reported.[12]

Administration. Health literacy assessments were administered in sequential patients enrolled in the DLR, during the patients' routine clinic visits. Each patient's initial LKAT score within the study time period was utilized. Due to the COVID-19 pandemic, not all patients were able to complete both the NVS and S-NUMI assessments; however, every patient had at least one of these assessments completed.

Analyses. Only patients with both an LKAT assessment and either the health literacy or numeracy assessment were included in the analysis. Differences in the correct responses to each LKAT question by health literacy and numeracy were analyzed descriptively by Fisher exact test. Unadjusted differences in mean LKAT score by health literacy and numeracy were analyzed by *t* tests. We performed univariate analyses to determine whether demographic variables were associated with the LKAT score. Multivariable linear regression models estimated the associations of health literacy and numeracy with the LKAT score, adjusting for education level. Additionally, a linear regression model was performed to determine the association between LKAT scores and disease activity, as measured by SLEDAI, clinical SLEDAI, and PGA, adjusted for education level. All statistical analyses were completed using SAS Version 9.4 (SAS Institute).

RESULTS

A total of 125 patients completed the LKAT, of whom 96 completed the health literacy assessment (NVS) and 85 completed the numeracy measure (S-NUMI); 56 completed both measures. LKAT scores were not different between those with both measures assessed and those with only 1 measure

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Table 1. Demographics.

	LKAT Cohort, n = 125	NVS Cohort, n = 96	S-NUMI Cohort, n = 85
Age, yrs, mean ± SD	42.7 (± 13.5)	42.9 (± 14.1)	41.5 (± 12.7)
SLE duration, yrs, mean ± SD (n = 118)	14.2 (± 8.3)	13.8 (± 8.3)	13.7 (± 8.1)
Female gender	119 (95)	91 (95)	81 (95)
Hispanic ethnicity (n = 124)	5 (4)	3 (3)	5 (6)
Race			
Black	70 (56)	51 (53)	53 (62)
White	47 (38)	39 (41)	26 (31)
Other	8 (6)	6 (6)	6 (7)
Education: college or higher (n = 122)	73 (60)	57 (60)	49 (60)
Medicare/Medicaid (n = 121)	55 (45)	45 (48)	33 (41)
Annual household income ≤ $50,000 (n = 114)	70 (61)	55 (62)	49 (63)
Disability or not working for pay (n = 118)	48 (41)	39 (42)	33 (42)
LN history (n = 119)	54 (45)	39 (43)	37 (44)
Active LN at visit (n = 119)	16 (13)	13 (14)	11 (14)
SLEDAI, mean ± SD (n = 113)	3.0 (± 3.3)	3.2 (± 3.4)	3.1 (± 3.2)
PGA, mean ± SD (n = 123)	0.6 (± 0.6)	0.6 (± 0.6)	0.6 (± 0.5)

Values are expressed as n (%) unless otherwise indicated. LKAT: Lupus Knowledge Assessment Test; LN: lupus nephritis; NVS: Newest Vital Sign; PGA: physician global assessment; SLE: systemic lupus erythematosus; SLEDAI: Systemic Lupus Erythematosus Disease Activity Index; S-NUMI: Numeracy Understanding in Medicine Instrument, Short Version.

available. If a patient answered all but 1 question, this blank question was considered incorrect, with a sensitivity analysis removing patients who did not respond to all 4 questions demonstrating similar results.

The mean age of patients was 42.7 years, and most were female (95%; Table 1). More than half of patients were Black (56%), and 4% of patients were Hispanic. Most patients had a college education or higher (60%). Forty-five percent of the cohort had Medicaid or Medicare insurance; around 60% earned a household income ≤ $50,000 annually. Less than half (41%) were on disability or not working. While 45% had a history of LN, only 13% had active LN at the visit. The mean SLEDAI was 3.0 and the PGA score was 0.6 out of 3. Demographics were similar between patients who had NVS and S-NUMI measures available (Table 1). In our cohort, 33% had limited health literacy, and 76% had limited numeracy.

Questions included as part of the LKAT are shown in Table 2, with the percentage of respondents answering each question correctly. All patients got ≥ 1 question correct, with 17% of the cohort answering all 4 questions correctly, 48% answering 3 questions correctly, 26% answering 2 questions correctly, and 9% answering only 1 question correctly. The mean LKAT score was 2.7 out of 4.0.

The vast majority of patients correctly responded to 3 questions: the reason for blood and urine monitoring (84%); HCQ prevented SLE flares (91%); and factors that contribute to fatigue in patients with SLE (74%). SLE was the factor most recognized as contributory to fatigue (n = 118, 94% correct), followed by insomnia (n = 105, 84%) and depression (n = 97, 78%). Only 23% were able to identify which UPC ratio > 1000 mg/g out of the following choices: 300 mg/g, 800 mg/g, 2300 mg/g, and not sure. Over half of patients indicated that they were not sure of the answer (58%), with an additional 15% failing to provide an answer for the question. In a sensitivity analysis removing patients who left a question blank, a similar proportion of patients answered each question correctly with an average LKAT score of 2.9 (compared to 2.7).

Table 2. Lupus Knowledge Assessment Test (LKAT)

Question	Correct Answers, n (%) n = 125
(1) My doctor does blood work and urine to check for:	
❑ Lupus activity	
❑ Side effects from lupus medications	
☑ Both lupus activity and side effects from medication	105 (84)
(2) Plaquenil (hydroxychloroquine) helps prevent lupus flares.	
☑ True	
❑ False	114 (91)
(3) In lupus patients, fatigue can be caused by which of the following? Check all that apply:	
☑ Lupus	
☑ Depression	
☑ Trouble sleeping (insomnia)	93 (74)
(4) Which of the following UPC lab ratios is > 1000 (mg/g), a sign that may indicate that a patient has active lupus nephritis?	
❑ 300 mg/g	
❑ 800 mg/g	
☑ 2300 mg/g	
❑ Not sure	29 (23)
Mean LKAT Score (SD)	2.7 (0.8)

☑ indicates correct answer. UPC: urine protein to creatinine ratio.

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Given that some of the patients did not have a history of LN, we assessed whether scores on the proteinuria question differed between patients with a history of LN vs those without LN. Comparing patients with and without a history of LN, there was a trend for a higher percentage of patients with a history of LN to answer the proteinuria question correctly (31% vs 17%; $P = 0.08$).

When compared to patients with adequate health literacy, those with limited health literacy had a lower overall LKAT score (Table 3). Fewer patients with limited health literacy responded correctly to the questions about reasons for blood and urine testing and the causes of fatigue. However, they had similarly high knowledge about HCQ preventing flares and similarly low knowledge about the UPC ratio. When compared to patients with adequate health numeracy, those with limited health numeracy had a similar overall LKAT score. Only the numerically focused question about the UPC elicited lower rates of correct response among those with limited numeracy.

Among the 56 patients with both measures, 20% had both adequate literacy and numeracy, and these patients had the highest mean LKAT score (3.2). All the patients with low literacy also had low numeracy, and these patients had the lowest mean LKAT score (2.5). Almost half of the patients had adequate literacy but low numeracy, and these patients had a mean LKAT score (3.0), in between the other 2 groups. A higher proportion of the cohort had a score of 100% (4.0 out of 4.0) in the adequate health literacy and numeracy group compared to the limited groups (Figure 1).

In a univariate analysis evaluating the association of demographic variables with LKAT score, college education level was the only factor associated with LKAT score ($P = 0.002$). In multivariable linear regression models, patients with adequate health literacy answered on average 0.71 more questions correctly (had a mean LKAT score 0.71 points higher) than patients with limited health literacy ($\beta = 0.71$, 95% CI 0.36–1.06), after adjusting for education level (Table 4). There was no association between adequate health numeracy and LKAT score. Additionally, there was no association between LKAT score and SLE disease activity (SLEDAI, clinical SLEDAI, or PGA; data not shown).

DISCUSSION

In our academic center cohort of patients with SLE, 33% had limited health literacy, and 76% had limited numeracy. Limited health literacy, but not numeracy, was associated with lower knowledge about SLE as measured by the LKAT after adjusting for education level. Patients with limited health literacy were more likely to miss questions assessing specific aspects of SLE knowledge, including understanding the reasons for blood and urine monitoring as well as multifactorial contributors to fatigue in SLE, compared to patients with adequate health literacy. In contrast, patients with limited numeracy were more likely to miss the proteinuria question than patients with adequate numeracy, but both groups answered the knowledge questions similarly. This suggests that health literacy and numeracy are separate, albeit interrelated, domains and that patients with limited literacy vs numeracy may have difficulty with different components of SLE knowledge and/or completing the written test questions. Additionally, patients with both limited health literacy and numeracy may be at particularly high risk for inadequate understanding and adverse outcomes. In our particular cohort, there was no association between LKAT score and SLE disease activity; however, previous work from our group has demonstrated an association between limited numeracy and higher disease activity.[12]

Patients especially struggled with the question about the UPC ratio, with only 23% responding correctly and 73% not providing an answer or responding "not sure." Low scores on this question were found regardless of adequate literacy and/or numeracy, possibly indicating a lack of understanding of UPC and/or difficulty interpreting the question (due to sentence complexity or interpreting the ">" symbol). Even among patients

Table 3. Responses to SLE-related knowledge questions stratified by health literacy and numeracy.

	Health Literacy (NVS)		
	Adequate, n = 64	Limited, n = 32	*P*
Q1 My doctor does blood work and urine to check for [what]?	59 (92)	22 (69)	0.006
Q2 Plaquenil (hydroxychloroquine) helps prevent lupus flares.	59 (92)	28 (88)	0.5
Q3 In lupus patients, fatigue can be caused by which of the following? Check all that apply.	56 (88)	16 (50)	0.0001
Q4 Which of the following UPC lab ratios is > 1000 (mg/g)?	18 (28)	5 (16)	0.2
Mean LKAT score (SD)	3.0 (0.8)	2.2 (0.8)	< 0.0001
	Numeracy (S-NUMI)		
	Adequate, n = 20	Limited, n = 65	*P*
Q1 My doctor does blood work and urine to check for [what]?	15 (75)	58 (89)	0.1
Q2 Plaquenil (hydroxychloroquine) helps prevent lupus flares.	18 (90)	60 (92)	0.7
Q3 In lupus patients, fatigue can be caused by which of the following? Check all that apply.	18 (90)	46 (71)	0.1
Q4 Which of the following UPC lab ratios is > 1000 (mg/g)?	9 (45)	14 (22)	0.05
Mean LKAT score (SD)	3.0 (0.9)	2.7 (0.8)	0.3

Values are expressed as n (%) unless otherwise indicated. LKAT: Lupus Knowledge Assessment Test; NVS: Newest Vital Sign; SLE: systemic lupus erythematosus; S-NUMI: Numeracy Understanding in Medicine Instrument, Short Version; UPC: urine protein to creatinine ratio.

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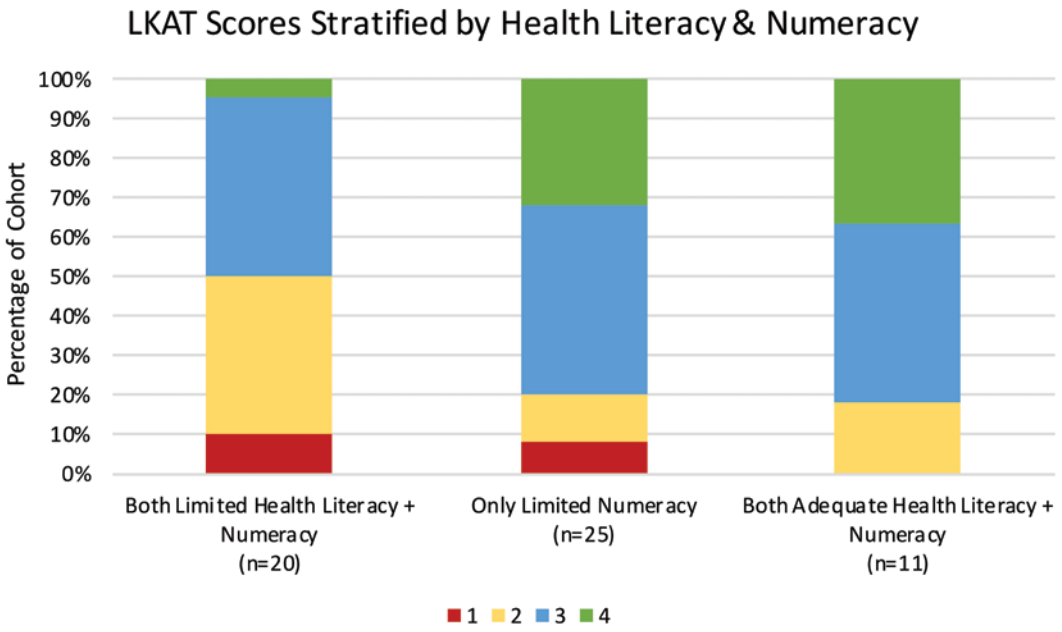


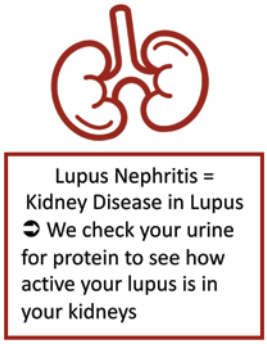
Figure 1. Patients with adequate health literacy and numeracy have higher mean LKAT score and a higher proportion of patients scoring 4 out of 4 on the LKAT, while those with limited health literacy and numeracy had the lowest mean LKAT score and overall lower LKAT performance. LKAT: Lupus Knowledge Assessment Test.

Table 4. Multivariable linear regression models of health literacy and numeracy on SLE knowledge.

	β (95% CI)	*P*	Adjusted β (95% CI) *	*P*
Health literacy	0.78 (0.45–1.12)	< 0.0001	0.71 (0.36–1.06)	< 0.0001
Health numeracy	0.26 (–0.15 to 0.67)	0.20	0.27 (–0.13 to 0.67)	0.20

* β adjusted for education level. SLE: systemic lupus erythematosus.

with a history of LN, few answered the proteinuria question correctly; this is particularly remarkable given a long average disease duration in our cohort of 14 years. This general inability to interpret the written UPC brings into question how we traditionally discuss proteinuria with patients, referencing the UPC ratio. Instead of relying on verbal explanation and/or numerical interpretation of the UPC, supplementing verbal explanations with a color-coded graph (similar to the current Asthma Action Plans with green zone for doing well, yellow zone for caution, and red zone for danger) might improve patient understanding of this important measure of SLE activity and damage[28,29] (Figure 2). A previous study found that individuals with HIV with higher health literacy were more likely to know their CD4 cell counts and viral loads.[30] Likewise, presenting LN in a health literacy–sensitive way such as a "lupus nephritis action plan" modeled in Figure 2. A better understanding of LN severity could help patients appreciate the status of their disease and its related consequences, and therefore improve self-management, including medication adherence.



	What this Means?	Level of Protein in the Urine (mg/g)	Your Level Today
RED ZONE:	Active Disease	≥ 1000	
YELLOW ZONE:	Caution	≥ 500	
GREEN ZONE:	Disease is Controlled (Doing Well)	< 500	

Figure 2. Health literacy–sensitive model for explaining lupus nephritis modeled after the Asthma Action Plan.[28,29]

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Limitations of this study are its cross-sectional nature to describe associations, where causation cannot be inferred. We recruited patients from a single academic center, limiting the generalizability of findings to other populations. While our patient population is racially diverse, our cohort does not have many patients of Hispanic ethnicity or limited English proficiency based on local demographics. Finally, the LKAT questions were determined through expert consensus guidance and have neither been validated nor have undergone psychometric testing. However, the association of limited health literacy with lower LKAT scores and limited numeracy with the UPC question suggest the LKAT has good face validity and could serve as a short proxy measure to assess SLE knowledge, particularly given the absence of any SLE-specific validated health literacy or numeracy measures. An additional limitation was that we had only 1 health literacy or numeracy test for some patients who did not complete both surveys; however, the 2 cohorts did have similar demographic characteristics, as noted in Table 1. Future work could consider assessing the reliability and validity of the LKAT, incorporating patient feedback, expanding question items to assess more nuanced domains of understanding related to SLE management, and having an increased sample size.

Given that limited health literacy and numeracy is associated with worse patient-reported outcomes and higher disease activity in SLE,[11,12] these domains are important to consider when counseling patients. Limited health literacy may contribute to worse outcomes by affecting patient knowledge, healthcare access, patient–provider interactions, and patient self-care.[10] Numeracy may play a role in suboptimal medication management, particularly for patients on complex medication regimens, which often exceed 50 tablets weekly. Further, limited numeracy may affect patients' understanding of the relative risks of complications from SLE comorbidities or the consequences of nonadherence.[31] Providers should be aware of the high rates of low health literacy in SLE and should practice health literacy universal precautions when counseling within the clinical encounter, treating all patients as though they potentially may have difficulty understanding and accessing health information.[32] By improving communication with patients, ensuring patients have adequate understanding and knowledge of their disease, and simplifying instructions and medication regimens, we may be able to improve outcomes and patient–physician relationships in this vulnerable patient population.

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