Investigating Health Literacy in Systemic Lupus Erythematosus: a Descriptive Review

Mithu Maheswaranathan[1,2], **Sarah Cantrell**[3], **Amanda M. Eudy**[1], **Jennifer L. Rogers**[1], **Megan E. B. Clowse**[1], **Susan N. Hastings**[4,5], **Stacy Cooper Bailey**[6]

[1]Division of Rheumatology & Immunology, Duke University, Durham, NC, USA

[2]Duke University Medical Center, DUMC 2918, Durham, NC 27710, USA

[3]Duke Medical Center Library & Archives, Duke University School of Medicine, Durham, NC, USA

[4]Departments of Medicine & Population Health Sciences and Center for the Study of Aging, Duke University, Durham, NC, USA

[5]Center of Innovation to Accelerate Discovery and Practice Transformation, Durham VA Health Care System, Durham, NC, USA

[6]Division of General Internal Medicine & Geriatrics, Feinberg School of Medicine, Northwestern University, Chicago, IL, USA

Abstract

Purpose of Review—Inadequate health literacy is common among American adults, but little is known about the impact of health literacy in rheumatic diseases. The purpose of this article is to review studies investigating health literacy and its association with clinical outcomes in systemic lupus erythematosus (SLE).

Recent Findings—Several validated health literacy measures have been examined in SLE patients. Low health literacy is associated with worse patient-reported outcomes and lower numeracy with higher disease activity. Two studies found no association of low health literacy with medication adherence. One randomized controlled trial tested a medication decision aid among patients with low health literacy.

Summary—We found a paucity of studies exploring health literacy in SLE. Low health literacy is associated with worse patient-reported outcomes and limited numeracy with higher disease activity in SLE. Further studies are needed exploring the impact of low health literacy on clinical outcomes and the effectiveness of literacy-sensitive interventions.

Keywords

Systemic lupus erythematosus; Health literacy; Numeracy; Lupus

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✉Mithu Maheswaranathan, mithunan.maheswaranathan@duke.edu.

Introduction

Health literacy is defined as the degree to which individuals have "the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [1]. Adequate health literacy is required to complete tasks like reading and comprehending prescription bottles, understanding health-related materials, using medical tools like a thermometer or blood pressure cuff, and managing medications. Low or inadequate health literacy is associated with poor health outcomes including increased hospitalizations, higher readmission rates, greater use of emergency care, poorer medication adherence, and worse disease activity [2–8]. Low health literacy has a substantial cost burden and is estimated to cost the US economy between $106 and $238 billion USD annually [9]. By better understanding the impact of health literacy in rheumatic diseases, we can address this risk factor in patient interactions, with a goal to ultimately improve health outcomes.

Health literacy may be especially salient in chronic rheumatic diseases such as systemic lupus erythematosus (SLE). Patients with SLE often have multi-system organ involvement and complex medication regimens, making health literacy important for effective disease management. For instance, patients with a new diagnosis of lupus nephritis are often started on induction therapy requiring up titration of mycophenolate mofetil with concomitant tapering of high-dose prednisone. Even the maintenance therapy regimen for a patient with lupus nephritis is very complex and easily exceeds 50 tablets weekly. Additionally, SLE patients have a variety of other health-related tasks they must complete to manage their disease including attending frequent clinic visits, undergoing laboratory testing, understanding disease-related symptoms, and negotiating medication costs with insurance companies. All of these tasks require high health literacy to accomplish successfully.

Despite the importance of health literacy to the effective management of SLE, this body of work has not been comprehensively reviewed or synthesized. A better understanding of the research that has been conducted to date will help determine current knowledge and identify gaps that should be addressed in future health literacy studies. Thus, the purpose of this analytical review is to broadly identify and characterize research from the scientific literature on the relationship between health literacy and SLE.

Methods

Sources and Search Strategy

For this descriptive review, we conducted a literature search in MEDLINE (via PubMed) from inception to August 2020 using a combination of keywords searched as text words and database-specific subject headings for the following concepts: health literacy and systemic lupus erythematosus. The full search strategy used was: ("Health Literacy"[Mesh] OR "health literacy"[tw] OR "health literate"[tw]) AND ("Lupus Erythematosus, Systemic" [Mesh] OR "systemic lupus erythematosus"). No restrictions were placed by date or language. Additionally, the American College of Rheumatology (ACR) conference online abstract portal (2012–2019) was reviewed for relevant abstracts on health literacy in SLE

and used to identify corresponding papers. Additional articles were considered by mining the references of relevant articles to identify others for inclusion.

Eligibility Criteria

Articles were included for this review if they met the following inclusion criteria: (1) described original research, (2) published in a peer-reviewed journal, (3) measured health literacy using a previously validated health literacy or numeracy assessment, and (4) included adult or pediatric patients with a diagnosis of SLE by ACR or SLICC classification criteria. Articles in any language were included. Searches were run from inception; we did not limit by publication date.

Study Selection, Data Abstraction, and Analysis

To select studies, one study author (MM) conducted a full-text review of all articles identified from the MEDLINE search. Data were abstracted from selected articles by one study author (MM) using a standardized form that captured information on study design, study population, health literacy measures utilized, outcomes evaluated and findings. Abstracted data were then compiled, reviewed and summarized in table format.

Results

A total of 11 articles were returned from the primary search in MEDLINE. Seven articles were excluded given they did not utilize a validated measure of health literacy. The majority of these articles discussed health literacy (for instance, as being important for clinical trial enrollment or theoretically improving quality of life) but did not explicitly investigate health literacy in the research study. Thus, four articles met eligibility criteria for inclusion; reference mining and the ACR abstract portal searches identified two additional articles for a total of six articles. The six articles included underwent data abstraction (MM). All articles included in the final review are summarized in Table 1.

Overview of Health Literacy in SLE

Of the six studies included in our review, five were observational, cross-sectional studies and one was a randomized controlled trial. Diverse populations with various racial and ethnic groups were included in the majority of the studies. The six studies recruited a total of 1020 patients with SLE across 5 studies in the USA and 1 study in Barbados. The rates of limited health literacy in SLE were reported in 4 of the 6 studies, these ranged from 8.5 to 48%.

Measurement of Health Literacy

A number of validated assessments of health literacy were utilized across studies, including the Rapid Estimate of Adult Literacy in Medicine (REALM) and REALM-SF ($n = 2$), the Short Assessment of Health Literacy tool (SAHL) ($n = 1$), Newest Vital Sign (NVS) ($n = 1$), Brief Health Literacy Screener (BHLS) ($n = 1$), and Shortened Test of Functional Health Literacy in Adults (STOFHLA) ($n = 1$) [10–15]. Only one study specifically evaluated numeracy, by a Rasch-based measure. A description of each of these measures is provided in Table 2. While many instruments have been developed, validated and utilized to assess health literacy over the past three decades [16–18], these measures often assess different

domains of health literacy, which can influence their relationship with outcomes; this has been described extensively in prior research [19, 20]. Different measures evaluate various skills such as reading fluency, comprehension, numeracy and/or functional health literacy; other measures are self-reported. Table 2 further describes the specific health literacy skills measured by each of the validated measures used in these studies.

Review of Specific Studies

Four of the studies evaluated an association between low health literacy with a clinical outcome in SLE. Clinical outcomes evaluated included medication adherence ($n = 2$), scores on patient-reported outcomes ($n = 1$), and disease activity by SLEDAI ($n = 1$). SLEDAI, Systemic Lupus Erythematosus Disease Activity Index 2000, was the validated measure selected to assess disease activity [21, 22]. One study was a randomized controlled trial, which investigated a literacy-sensitive medication decision aid for patients with lupus nephritis. Another study characterized the baseline health literacy and demographic predictors of low health literacy among patients with SLE, but did not examine any associations with clinical outcomes.

Evaluating Baseline Health Literacy and Demographic Predictors of Low Health Literacy

The earliest study published in the mid-1990s investigated the rate of low health literacy in 94 patients with SLE from a university clinic and private clinic using the REALM [23]. In their cohort, 48% had inadequate health literacy, as defined by REALM score below a 9th grade reading level. They found race (African American) and education level were demographic characteristics which influenced REALM scores in a multiple linear regression analysis. Additionally, they looked at the readability levels of lupus-specific written patient education materials (e.g., Arthritis Foundation, Department of Health and Human Services) and found that 89% of materials were written at a ninth-grade level or above. The authors highlighted the discrepancy between reading level of current SLE patient education materials (too high for most patients) and the reading literacy of lupus patients, and recommend a need to tailor future materials developed for SLE to be at appropriate reading levels.

Randomized Controlled Trial with a Health Literacy-Informed Medication Decision Aid

Given no patient decision aids are available for lupus medication decision-making, Singh et al. developed and tested a computerized decision aid for medication decision-making for patients with lupus nephritis [24]. They hypothesized low health literacy may interfere with the delivery of "guidance-concordant care" in racial and ethnic minorities with SLE. Thus, they sought to develop an individualized, culturally tailored computerized decision aid for medication decision-making for patients with lupus nephritis. Health literacy was determined by the Short Assessment of Health Literacy tool (SAHL-E and SAHL-S), subjective numeracy with the subjective numeracy scale, and graphical literacy using the short form version by Galesic and colleagues [14, 25, 26]. Women having a lupus nephritis flare and considering change or initiation of an immunosuppressive medication, or who had prior lupus nephritis flare and were at risk for future flare, were eligible. In this cohort of 301 women with lupus nephritis, 8.5% had low health literacy and 34% had low numeracy. Patients were randomized to a computerized decision aid or an American College of

Rheumatology patient information pamphlet. They found use of the decision aid resulted in a significant reduction in decisional conflict compared to the control pamphlet group, and there was no difference in the magnitude of the effect between high versus low health literacy groups. Significantly more patients in the decision aid group, compared to the pamphlet, rated information to be excellent for understanding lupus nephritis (49% versus 33%), risk factors (43% versus 27%) and medication options (50% versus 33%), and ease of use of materials was higher in the decision aid group [24]. The authors noted that this RCT was conducted in a diverse group of women with lupus nephritis, including those who were low income and had low health literacy, and demonstrated the culturally tailored patient decision aid was more effective than usual practice for immunosuppressive medication decision-making. Some limitations of the study included the exclusion of men, short follow-up period and lack of clinical outcomes assessed.

Association of Health Literacy with Medication Adherence

Few studies have investigated the implications of low health literacy on clinical outcomes in SLE, although two have evaluated the association of health literacy with medication adherence. A cross-sectional study of 106 women from Barbados found 21% of patients had inadequate health literacy using the abbreviated Rapid Estimate of Adult Literacy in Medicine Short Form [27, 28]. They explored the associations between medication adherence and health literacy using age-adjusted ordinal logistic regression models. Medication adherence was measured by the Morisky Medication Adherence Questionnaire (MAQ), a self-reported measure, which assesses a patient's ability to follow provider recommendations and maintain other health behaviors related to medication use. There was no statistically significant association between health literacy and the MAQ (OR 0.37; 95% CI 0.13–1.03; $p = 0.06$) [29]. The authors comment that factors beyond knowledge and understanding of health information may be influencing adherence. Additionally, they note the possibility of a U-shaped association with highest rates of non-adherence at the extremes of the health literacy spectrum. The authors noted a major limitation of their study is that adherence was measured by self-report.

One study from an academic center SLE cohort recently investigated association of non-adherence by hydroxychloroquine levels with disease activity, and evaluated health literacy as a covariate [30]. They defined non-adherence as having a blood hydroxychloroquine level of < 500 ng/mL. This threshold was selected based on prior studies, with a therapeutic cutoff at this level suggested by previous cohort data [31]. Health literacy was measured using the Newest Vital Sign (NVS), with limited health literacy defined as a score between 0 and 3. Health literacy did not have significant effect on medication adherence as measured by HCQ blood levels, with non-adherent patients having a median NVS score of 3.1 compared to adherent patients with median NVS of 2.9 ($p = 0.623$).

Health Literacy and Impact on Patient-Reported Outcomes

Recently a study evaluated the effects of health literacy on patient-reported outcomes (PROs), which play an important role in evaluating patient status in rheumatic diseases [32]. Many PRO instruments are not evaluated for reading level or comprehension prior to implementation. Given previous work demonstrated patients with limited health literacy

have more confusion in completing global assessments of rheumatoid arthritis (RA) activity [33] and limited health literacy predicts greater discordance between patient and provider assessment of disease activity in RA [34], the investigators sought to evaluate the impact of limited health literacy on PROs in a diverse SLE cohort. Limited health literacy was associated with significantly worse scores on all PROs (ten PROMIS short forms, eight SF-36 subscales, SLAQ and SLE activity) except disease damage (Brief Index of Lupus Damage, BILD) in multivariate analysis (controlling for education, income, and health literacy). PROMIS measures, or Patient-Reported Outcomes Measurement Information System, were developed as a resource for measurement of patient-reported symptoms, functioning and health-related quality of life across a wide variety of chronic diseases and conditions [35]. SF-36 is a 36-item Short Form Health Survey Questionnaire used to evaluate health-related quality of life [36]. SLAQ, the Systemic Lupus Activity Questionnaire, is a validated, self-report measure of SLE disease activity [37, 38]. The authors comment on the disparities in PROs needing further study to determine whether due to actual differences in health or measurement issues (for instance, patients with limited health literacy may have more difficulty completing the PRO assessment).

Health Numeracy, Numeric Confidence, and Lupus Disease Activity

Another study specifically evaluated numeracy in SLE, including objective numeracy as well as numeric self-efficacy [39]. Numeracy is a component of health literacy involving quantitative tasks or mathematical calculations. Objective numeracy relates to ability to do mathematical calculations while numeric self-efficacy refers to "confidence that provides engagement and persistence in numeric tasks." The study looked at a cohort of adult SLE patients from an academic medical center clinic. They measured objective numeracy [40], health literacy (by TOFHLA) [10], numeric confidence, and patient activation. SLE disease activity was assessed by the Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI). They found that among patients with more numeric confidence, having greater objective numeracy was associated with lower SLEDAI scores. Given low numeracy is associated with worse clinical outcomes, the authors highlight the potential benefit of numeracy interventions and the importance of providing tailored communication or assistance. For example, the authors suggest in medication titration, it may be helpful to provide patients a calendar which explicitly shows the number of pills to take each day.

We did not find any studies that evaluated the effect of interventions to improve health literacy or interventions designed specifically to improve outcomes for SLE patients with low health literacy. The study by Singh et al. did investigate the impact of a health literacy-informed medication decision aid in patients with lupus nephritis, including a proportion who had low health literacy. However, this was the only study that evaluated impact of an intervention related to health literacy in SLE through a randomized controlled trial.

Discussion

Our review demonstrates a limited understanding of the relationship between health literacy and lupus outcomes as well as potential interventions that can be implemented to reduce literacy-related health disparities. Only six studies to date have explicitly investigated health

literacy in SLE through validated assessment measures and four articles have evaluated the association of health literacy with clinical outcomes in SLE. Limited health literacy and numeracy were associated with worse patient-reported outcomes and higher disease activity in two of these studies. Thus, additional work is needed to explore the implications of limited health literacy on other clinical outcomes in SLE including patient/physician communication, self-efficacy, lupus-related morbidity, adherence with health maintenance behaviors, healthcare utilization, and mortality.

The body of evidence exploring health literacy in the context of other chronic diseases is much larger than in SLE and other rheumatic diseases. For instance, while HIV and lupus both affect similar numbers of people with just over 1 million people living with both illnesses in the USA [41, 42], we found 279 articles investigating health literacy in HIV using our search strategy compared to only 11 in SLE. This suggests a paucity of research in health literacy in SLE compared to another chronic disease of similar prevalence and the need for further study in lupus. Reassuringly, there appears to be an increasing interest in health literacy research in SLE and other rheumatic diseases. We performed a Web of Science search to determine the relative frequency of citations related to health literacy or numeracy in rheumatic diseases over time (SLE, rheumatoid arthritis, gout, vasculitis, scleroderma and myositis) and found citations increased from less than 20 prior to 2006 to over 200 citations annually since 2017.

The percentage of patients with less than adequate (i.e., limited) health literacy in SLE ranged from 8.5 to 48% depending on the study and health literacy measure. This wide variation is likely attributable to differences in health literacy measures used, with each assessing different specific health literacy skills, and the diversity of patient populations sampled. In this review, five different health literacy measures were utilized which assess different skills from reading ability and medical word fluency to interpretation of a nutrition label. Previous researchers have acknowledged the limitation of measurement of health literacy skills and measurement variation across different instruments [43]. Future studies should explore health literacy across multiple lupus patient populations to better determine the health literacy skills in this population.

Two studies demonstrated associations of limited health literacy and numeracy with worse patient-reported outcomes and disease activity. In the paper by Katz et al., limited health literacy was linked with worse PROs even after controlling for race/ethnicity and education level. They note in their discussion it is impossible to determine from their analyses whether the differences in PROs observed by health literacy were due to actual differences in health status, difficulty understanding or interpreting scale items, or unmeasured effects of health literacy. Similar findings have been demonstrated in inflammatory bowel disease where patients with limited health literacy have worse patient-reported outcomes (worse overall health and more depressive symptoms), and Crohn's patients with adequate health literacy were more likely to be in clinical remission [3]. These findings suggest future studies should investigate the association of limited health literacy with disease activity in SLE, and clarify whether the worse patient-reported outcomes is due to differences in understanding or interpretation of the PRO questions.

Two studies found no associations between low health literacy and medication adherence. It is plausible other factors unrelated to health literacy may be contributing to non-adherence including cost, difficulty tolerating medications or other factors. Yet these results should not be considered conclusive and additional research is likely needed. Studies were observational with small sample sizes; the study by Flowers et al. also used self-reported adherence, which is often poorly correlated with objective measures. Previous work has demonstrated poor correlation between subjective and objective measures of medication adherence in SLE [44]. Future work should include more rigorous measures of medication adherence (i.e., medication fill rates, like the medication possession ratio or proportions of days covered, or drug levels) and larger sample sizes to more accurately capture the relationship between health literacy and adherence within the context of SLE.

Our work identified only one study testing the impact of a literacy-informed intervention in patients with SLE; this randomized controlled trial by Singh et al. found the medication decision aid had significant reduction in reducing decisional conflict compared to a standard information pamphlet in patients with lupus nephritis [24]. More patients in the decision aid group rated information to be excellent for understanding lupus nephritis, risk factors and medication options. During development of the decision aid, these authors performed iterative testing and modification to ensure words, phrases and images were acceptable and could be easily comprehended considering the health literacy, numeracy and graphical literacy of the population [45]. While this intervention specifically incorporated health literacy principles to assess improving decisional conflict, we have not identified any studies in lupus testing health literacy interventions in improving more distal clinical outcomes. Previous health literacy-informed interventions have demonstrated improvement in health behaviors, clinical outcomes, and patient-reported outcomes in other disease entities as well as medication adherence in rheumatology patients [46, 47]. Thus, in addition to better understanding the impact of low health literacy in SLE, further study is also needed testing and determining the potential efficacy of health literacy-informed interventions in SLE patients in improving health-related and SLE outcomes.

From a clinical perspective, physicians should be aware of the potential negative impacts of low health literacy on health outcomes and engage in literacy-sensitive approaches to patient education in the clinical encounter. Given lack of accurate predictors of limited health literacy, it is recommended all providers maintain a universal precautions approach, utilizing clear communication strategies and plain language techniques for all patients regardless of presumed health literacy [48]. This universal approach is important given previous studies have demonstrated a physician assessment of a patient's literacy and patient educational level are poor predictors of health literacy level [49]. A recent study by Hirsh et al. evaluated adaption of a universal health literacy precautions toolkit to rheumatology and illustrated its effectiveness for significantly improving medication adherence, and disease activity in a subgroup of patients with rheumatoid arthritis over a 6 month intervention period [46, 50]. This intervention included educating physicians about health literacy communication principles including encouraging questions and the teach-back method [50], as well as incorporated a brown bag medication review. The brown bag medication review involved patients bringing medications to appointments to review what they were taking and dosing, answer patient questions and identify potential medication errors. It demonstrates an

example of how incorporating health literacy principles in the clinical encounter led to meaningful improvements in medication adherence including SLE patients and reduced disease activity among patients with RA.

We note several limitations to our descriptive review. A systematic review was not conducted of the entire literature. However, we did utilize reference mining strategies of identified articles and ACR abstract reviews in efforts to capture all relevant studies. Additionally, it is possible some relevant studies were excluded from the analysis, such as studies incorporating health literacy principles that did not measure health literacy in the study population. Despite these limitations, this review summarizes the knowledge to date on health literacy and numeracy among patients with SLE.

Conclusions

Findings from this descriptive analysis indicate limited health literacy is relatively common in SLE and likely contributes to worse lupus-related outcomes, including disease activity and patient-reported outcomes. Additional research is needed to explore the association between health literacy with other clinical outcomes and develop and evaluate interventions to reduce literacy-related health inequities in SLE. As demonstrated in other disease states, a more comprehensive understanding of the implications of limited health literacy can help elucidate the causal mechanisms by which health literacy influences these clinical outcomes, and subsequently inform development of interventions to help intervene in this pathway for patients with limited health literacy. By better understanding and appreciating the role of health literacy in SLE, we can better tailor our efforts in clinical care, patient education, and testing of interventions to ultimately help improve outcomes in SLE. Given the inherent complexities of managing SLE including multi-system organ involvement, frequent clinic visits, high rates of fatigue and concomitant depression or fibromyalgia, and often difficult medication regimens, creating novel health literacy-informed interventions could be a unique way to help improve quality of life, disease understanding, and other health outcomes in SLE.

Conflict of Interest

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Table 1

Studies investigating health literacy in specific rheumatic diseases (or SLE)

	Design	Sample	Health literacy measure (% < adequate)	Study objective + outcomes evaluated	Results
Systemic lupus erythematosus					
Hearth Holmes et al. (1997) [23]	Cross-sectional	$n = 94$	REALM (48%)	Objective: assess baseline literacy and evaluate reading level of patient education materials Outcomes: what are predictors of low health literacy	• Race (African American) and education level predicted reading ability by REALM • Most patient education materials were written above an 11th grade level
Flower et al. (2016) [27]	Cross-sectional	$n = 106$	REALM-SF (21%)	Objective: evaluate effects of self-efficacy, health literacy, and neuro-psych lupus on medication adherence Outcomes: health literacy as a predictor of medication adherence (as measured by the MAQ, Morisky's Medication Adherence Questionnaire)	No strong relationship between MAQ score and health literacy
Singh et al. (2019) [24]	Multi-center, open-label RCT	$n = 298$	Short Assessment of Health Literacy tool, SAHL-E, SAHL-S (8.5%), Subjective Numeracy Scale (34%), Galesic Graphical Literacy	Objective: evaluate decision aid impact on decisional conflict compared to ACR lupus pamphlet, health literacy was measured Outcomes: decisional conflict	Significant reduction in decisional conflict with the decision aid, no difference in the magnitude of effect between low vs high literacy groups
Geraldino-Pardilla et al. (2018) [30]	Cross-sectional	$n = 108$	Newest Vital Sign (not reported)	Objective: evaluate association of HCQ level with disease activity, HL was a covariate Outcomes: association with non-adherence, defined as blood HCQ level < 500 ng/mL	No significant association between health literacy and adherence
Katz et al. (2020) [32]	Cross-sectional	$n = 323$	Brief Health Literacy Screener, Chew Items (38%)	Objective: determine the independent effect of health literacy, income and education on PROs in SLE Outcomes: PROs (PROMIS, SF-36, SLAQ)	LHL was associated with significantly worse scores on all PROs except disease damage (multivariate analysis considering education, income, HL)
Peters et al. (2019) [39]	Cross-sectional	$n = 91$	STOFHLA, Objective and Numeracy by Rasch-based measure (not reported)	Objective: determine impact of numeracy (and numeric confidence) on disease activity (SLEDAI) Outcomes: disease activity (SLEDAI)	Greater objective numeracy was associated with lower SLEDAI scores, among patients with more numeric confidence.

Only includes studies where health literacy was measured by a specific, validated assessment

Table 2

Validated measurements of health literacy

Assessment name		Abbreviation	# items	Specific skills measured
Objective Measures	Rapid Estimate of Adult Literacy in Medicine (13)	REALM	66	• Medical word fluency • Scored based on ability to read and pronounce 66 common medical words
	Rapid Estimate of Adult Literacy in Medicine, Short Form (11)	REALM-SF	7	• Abbreviated test of medical word fluency • Scored based on ability to read and pronounce 7 common medical words
	Short Assessment of Health Literacy (14)	SAHL	18	• Tests ability to read and understand common medical terms • Participants identify which of two words is more similar to, or has a closer association with, a provided medical word
	Newest Vital Sign (15)	NVS	6	• Assesses analytical and conceptual skills needed to read and interpret a nutrition label
	Shortened Test of Functional Health Literacy in Adults (10)	STOFHLA	40	• Shortened version of the TOFHLA • Measure of ability to read and comprehend health-related materials, also 4 numeric calculations assessing numeracy
Self-Report	Brief Health Literacy Screener (12)	BHLS	3	• Self-reported measure completed by patient • Asks to rate difficulty learning about one's medical condition, reading hospital materials, and ability to fill out medical forms oneself