# Investigating Health Literacy and Numeracy in Lupus and Associations with Disease Activity

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## INTRODUCTION

SLE is a chronic disease with inherent complexity including medication regimens and multi-organ disease manifestations. Health literacy skills are critical to help patients understand disease, manage medications and navigate the healthcare system. Low health literacy may play a role in worse disease outcomes and health disparities in SLE.

**Health literacy** is the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.

- Over **33%** of US adults have basic or below basic health literacy.
- Cost of low health literacy to US economy: $106-$238 billion annually

**Health numeracy** is a form of quantitative health literacy:

- Over **50%** of US adults have basic or below basic numeracy skills

Low heath literacy is associated with worse clinical outcomes in other disease states, but limited data exists addressing impact of low health literacy in SLE. The objectives of this research were to:

1. assess baseline health literacy and numeracy of our SLE cohort
2. evaluate clinical associations with low health literacy/numeracy including lupus disease activity (by proteinuria and PGA)

## METHODS

SLE patients at an academic university Rheumatology clinic were recruited and interviewed from March-Sept 2019. Health literacy and numeracy were assessed by validated survey instruments [see below]. Demographic information was also elicited, and chart review performed to obtain additional clinical factors. Fisher's exact test or t-tests were performed for categorical or continuous variables, using STATA Version 15. Associations between health literacy and numeracy with clinical variables were analyzed using univariate and multivariate models.

| | Health Literacy Assessment | Description |
|---|---|---|
| OBJECTIVE | Rapid Estimate of Adult Literacy in Medicine (**REALM**) | medical vocabulary fluency through 66 common medical words |
| OBJECTIVE | Arthritis-Adapted Rapid Estimate of Adult Literacy in Medicine (**A-REALM**) | medical vocabulary fluency through 66 arthritis related words |
| OBJECTIVE | Newest Vital Sign (**NVS**) | interpretation of a nutrition label to assess health literacy/numeracy |
| OBJECTIVE | Numeracy Understanding in Medicine Instrument, Short Version (**S-NUMi**) | 8 math questions involving numbers and proportions to assess numeracy |
| SUBJECTIVE | Basic Health Literacy Screen (**BHLS**) | self-reported health literacy ability including 3 questions scored 0-4 |
| SUBJECTIVE | Shortened Subjective Numeracy Scale (**SNS-3**) | self-reported health numeracy skills by 3 question survey assessing perception of mathematical abilities |

## RESULTS

**Table 1: Associations with Low Health Literacy**

| | High | Low | p-value |
|---|---|---|---|
| | n=25 | n=16 | |
| **Female** | 23 (92%) | 15 (94%) | 1.0 |
| **Black** | 12 (48%) | 15 (94%) | 0.003 |
| **History of Lupus Nephritis** | 12 (48%) | 7 (44%) | 1.0 |
| **Cognitive Dysfunction** ∗ (n=33) | 13 (62%) | 7 (58%) | 1.0 |
| **College Graduate** (n=40) | 16 (67%) | 9 (56%) | 0.5 |
| **Medicaid Insurance** (n=39) | 7 (30%) | 10 (63%) | 0.06 |
| **Disability** (n=39) | 9 (39%) | 7 (44%) | 1.0 |
| **Income <$50,000** (n=38) | 12 (50%) | 14 (100%) | 0.001 |
| **PHQ-9 Depression** (n=29) | 3 (17%) | 1 (9%) | 1.0 |
| | **Mean (SD)** | **Mean (SD)** | **p-value** |
| **Age** | 40.2 (11.7) | 41.0 (12.0) | 0.8 |
| **Medication Adherence** ± (n=37) | 89.6 (11.9) | 84.1 (18.0) | 0.3 |
| **Clinical SLEDAI** | 2.0 (2.7) | 1.5 (2.9) | 0.6 |
| **PGA1** | 0.7 (0.6) | 0.6 (0.7) | 0.8 |
| **PGA2** (n=40) | 0.8 (0.7) | 0.7 (0.7) | 0.6 |
| **UPC** § | 191.4 (268.3) | 229.4 (304.7) | 0.7 |
| **FSS** ● (n=36) | 9.4 (7.0) | 7.8 (7.1) | 0.5 |

Patients with low health literacy were more likely to be African American, have Medicaid insurance and income less than $50,000 annually.

Legend

**Cognitive Dysfunction** ∗: self-reported cognitive dysfunction over past 1 month
**Medication Adherence** ±: self-reported adherence over the past 1 month
**UPC** §: urine protein to creatinine ratio
**FSS** ●: fibromyalgia symptom severity score

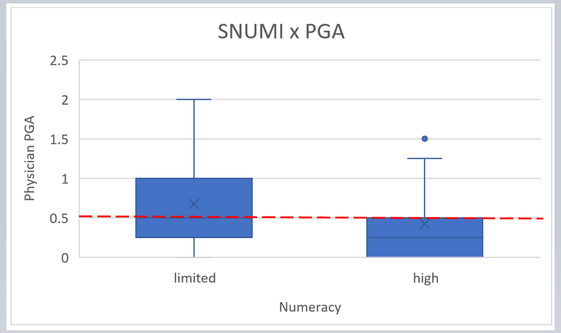


**Figure 1**: Relationship between **Numeracy** with **Lupus Disease Activity**, as measured by PGA (Physician Global Assessment)

**Table 2: Associations with Low Health Numeracy**

| | High | Low | p-value |
|---|---|---|---|
| | n=25 | n=67 | |
| **Female** | 23 (92%) | 63 (94%) | 0.7 |
| **Black** | 9 (36%) | 48 (73%) | 0.002 |
| **History of Lupus Nephritis** | 13 (52%) | 28 (42%) | 0.5 |
| **Cognitive Dysfunction** ∗ (n=79) | 11 (55%) | 37 (63%) | 0.6 |
| **College Graduate** (n=89) | 15 (63%) | 40 (62%) | 1.0 |
| **Medicaid Insurance** (n=88) | 4 (17%) | 31 (48%) | 0.007 |
| **Disability** (n=85) | 4 (17%) | 24 (39%) | 0.07 |
| **Income <$50,000** (n=84) | 12 (50%) | 39 (65%) | 0.2 |
| **PHQ-9 Depression** (n=68) | 2 (11%) | 8 (16%) | 1.0 |
| | Mean (SD) | Mean (SD) | p-value |
| **Age** | 40.6 (9.3) | 41.4 (13.3) | 0.7 |
| **Medication Adherence** ± (n=87) | 81.7 (28.8) | 83.2 (21.1) | 0.8 |
| **Clinical SLEDAI** | 1.2 (2.1) | 1.7 (2.6) | 0.3 |
| **PGA1** (n=91) | 0.4 (0.5) | 0.7 (0.6) | 0.05 |
| **PGA2** (n=90) | 0.6 (0.7) | 0.7 (0.7) | 0.3 |
| **UPC** § | 114.6 (105.1) | 501.6 (1201.6) | 0.01 |
| **FSS** ● (n=85) | 8.3 (4.9) | 8.9 (7.1) | 0.7 |

Patients with low health numeracy were more likely to be African American and have Medicaid insurance. Additionally, those with low numeracy had higher PGA1 scores and higher levels of proteinuria ($p < 0.05$).

### Prevalence of Low Health Literacy/Numeracy:


➲ 39% have low (limited) health literacy [as measured by NVS]


➲ 73% have low to medium health numeracy [as measured by S-NUMI]

### Examples of Validated Literacy Instruments

**Panel 1:** A-REALM


**Panel 2:** NVS

## KEY POINTS

1. The prevalence of low health literacy in our academic center lupus cohort is 39% and rate of low health numeracy of 73%.

2. Patients with lower health literacy were more likely to be African American, have Medicaid insurance, and have income <$50K annually.
   ➲ There was no association between lower health literacy/numeracy and FSS score, cognitive dysfunction or self-reported medication adherence.

3. Those with lower health numeracy have higher disease activity, as measured by PGA.

**Low health literacy** was associated with African American race and low SES factors. Patients with **lower numeracy** had higher disease activity.

## CONCLUSIONS

Future studies are needed to investigate the impact of low health literacy on additional disease outcomes in SLE. Low health literacy may be a contributing factor to healthcare disparities in SLE, which can be targeted in future patient interventions.

## REFERENCES

1) Kutner M, G.E., Jin Y, Paulsen C. , The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy. 2003.
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