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Authors

Tift, Benjamin
Dunlop-Thomas, Charmayne
Sam Lim, S
et al.

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Geriatric Assessment of Physical and Cognitive Functioning in a Diverse Cohort of Systemic Lupus Erythematosus Patients: A Pilot Study

Laura Plantinga, PhD[1], **Benjamin D. Tift, MPH**[2], **Charmayne Dunlop-Thomas, MS, MPH**[1], **S. Sam Lim, MD, MPH**[1], **C. Barrett Bowling, MD, MSPH**[3], and **Cristina Drenkard, MD, PhD**[1]

[1]Department of Medicine, Emory University, Atlanta, Georgia

[2]Edward Via College of Osteopathic Medicine, Spartanburg, South Carolina

[3]Durham Veterans Affairs Geriatric Research Education and Clinical Center, Durham Veterans Affairs Medical Center (VAMC), and Department of Medicine, Duke University, Durham, North Carolina

Abstract

Objective—To use multi-domain functional assessment, commonly performed in geriatric patients but novel among SLE patients, to better understand functional impairment in SLE.

Methods—We recruited 60 adult participants [aged 20–39 (26.7%), 40–59 (50.0%), and ≥60 (23.3%); 80.0% black; 90.0% female] from an existing cohort of SLE patients. During in-person visits (10/16–4/17), we evaluated physical performance (range 0–4; higher scores = better performance); cognitive performance (five fluid cognition domains; adjusted t-scores); and self-reported measures including physical functioning (t-scores), activities of daily living (ADLs), falls, and life-space mobility.

Results—Mean (±SD) balance (3.7±0.8) and gait speed (3.4±1.0) scores were high, while the mean lower body strength score was low (1.8±1.3). Cognitive performance was average (score=50) for episodic (47.7±9.2) and working (48.6±11.2) memory and low average for cognitive flexibility (43.7±14.2), processing speed (42.6±14.8), and attention/inhibitory control (38.8±8.6; >1 SD below average), compared to healthy individuals of the same age, sex, race, ethnicity, and education. Most participants reported independence in basic ADLs but many reported dependence in instrumental ADLs. Nearly half (45.0%) of participants reported falling in the prior year. Only 40.0% reported unlimited ability to travel without the help of another person. Scores generally did not differ substantially by age.

Conclusion—Our results suggest high prevalence of impairment across multiple domains of function in SLE patients of all ages, similar to or exceeding the prevalence seen in much older

Corresponding Author: Laura Plantinga, Divisions of Renal Medicine and General Medicine and Geriatrics, Department of Medicine, Emory University, 101 Woodruff Circle, 5105 Woodruff Memorial Building, Atlanta, GA 30322. Phone: 404-727-3460; Fax: 404-727-3425; laura.plantinga@emory.edu.
DR. LAURA PLANTINGA (Orcid ID : 0000-0003-0809-8981)
DR. CRISTINA DRENKARD (Orcid ID : 0000-0002-6832-7291)

geriatric populations. Further research into the added value of geriatric assessment in routine care for SLE is warranted.

Systemic lupus erythematosus (SLE) is associated with multiple comorbid conditions and non-disease-specific manifestations. Even relatively young SLE patients perceive substantial impairments in physical (1–5) and cognitive (6–10) function, generally considered geriatric syndromes (11). Such independence-limiting restrictions may serve as important patient-centered outcomes (12) and are being used in geriatrics and medical subspecialties, such as oncology (13, 14), to improve risk stratification, support self-management, and assess impact of treatments. However, to our knowledge, with the exception of frailty (15), the relevance of geriatric approaches—such as multi-domain functional assessment—to SLE has not been explored.

Preliminary studies of the ongoing, population-based Georgians Organized Against Lupus (GOAL) cohort of SLE patients showed poor physical functioning and high prevalence of cognitive symptoms, by self-report (16, 17). Based on the International Classification of Functioning, Disability and Health model (18), we hypothesized that both SLE-related factors and contextual (environmental and personal) factors contribute to poor functioning in SLE. To begin to address this hypothesis, we obtained detailed, in-person assessments of physical and cognitive functioning across multiple domains in an ancillary pilot study [Approaches to Positive, Patient-centered Experiences of Aging in Lupus (APPEAL)] among SLE patients recruited from GOAL. We aimed to estimate the prevalence of impairment across multiple physical and cognitive functioning domains and to examine whether physical and cognitive functioning differed by participant characteristics.

Patients and Methods

Study Population and Data Sources

We recruited SLE patients and utilized data from the ongoing GOAL cohort in metropolitan Atlanta. GOAL participants were recruited from the Georgia Lupus Registry, a population-based registry (19); the GOAL cohort was enriched with additional patients receiving SLE treatment in metropolitan Atlanta. GOAL recruitment and data collection details have been published previously (20). GOAL participants are adults (≥18 years) with a documented diagnosis of SLE [≥4 revised American College of Rheumatology (ACR) criteria (21), or 3 ACR criteria plus a diagnosis of SLE by an attending board-certified rheumatologist]. Inclusion criteria for the APPEAL pilot study were: black or white race, English-speaking, sufficient vision and hearing to undergo study testing, and ability to travel to an in-person study visit. The Emory Institutional Review Board approved the APPEAL and GOAL study protocols. All APPEAL participants provided informed consent.

A total of 107 GOAL participants were contacted by mail and phone to obtain the target sample size of 60 APPEAL participants (Figure S1). Data were obtained from a series of performance tests and questionnaires administered during study visits (10/16–4/17). In addition to the data collected during the in-person APPEAL visit via REDCap (22) and NIH Toolbox (23), self-reported data collected during the most recent annual GOAL assessment (6/16–1/17) were linked for each APPEAL participant.

Study Variables

Physical Performance—Physical performance was assessed via the Short Physical Performance Battery (SPPB) (24), which includes assessments of balance (ability to hold standing poses in different foot positions), gait speed (fastest of two 4-meter walks at usual pace), and lower body strength (speed in completing five chair stands without using arms). All individual tests were scored 0–4 (higher scores indicating higher levels of physical performance); the overall score was the sum of the three individual scores (range, 0–12).

Cognitive Performance—Cognitive performance was assessed via five individual assessments via the NIH Toolbox application (23, 25, 26): Picture Sequence Memory Test (measures episodic memory, or ability to remember objects, people, or events experienced at particular times and places), List Sorting Working Memory Test (measures working memory, or the ability to remember and see connections between items or ideas), Pattern Comparison Processing Speed Test (measures processing speed, or how quickly one can take in and use information), Flanker Inhibitory Control and Attention Test (measures attention and inhibitory control, or the ability to focus on relevant stimuli in the presence of irrelevant stimuli), and the Dimensional Change Card Sort Test (measures cognitive flexibility, or the ability to shift thoughts and adapt behavior to new conditions). Raw scores were converted to t-scores, adjusted for age, sex, race/ethnicity, and education. Fully adjusted t-scores (mean=50, SD=10) range from 0 to 100, such that 50 is the average score and 40 and 60 are 1 SD below and above the mean, respectively; higher scores indicate better cognitive functioning. Individual assessment scores were incorporated into a composite adjusted t-score measuring fluid cognition, or overall capacity to reason and solve novel problems. Adjusted t-scores were also converted to percentile ranks.

Self-Reported Functioning—Self-reported information on a variety of domains was collected via questionnaire.

Physical functioning: Self-reported physical functioning was measured via the PROMIS Physical Functioning-Short Form 12a (27). Raw scores (range, 0–100) were scaled to t-scores (range, 13.3–66.1), such that 50 represented the average score for a general adult population, differences of 10 represented 1 SD, and higher scores represented better self-reported physical functioning.

Activities of daily living: Basic activities of daily living (BADLs; *e.g.*, bathing, dressing, transferring) (28) and instrumental activities of daily living (IADLs; *e.g.*, shopping, managing finances) (29) scales provide dichotomous scores: ability to perform the activity independently or with minimal help (*e.g.*, shopping independently for all needs or only for small purchases) vs. inability to perform the activity without help (*e.g.*, needing to be accompanied on all shopping trips or being completely unable to shop).

Falls: Participants were asked how many falls they had had and whether they had sought medical attention for any of their falls in the past year. Fear of falling during daily tasks was assessed using the Falls Efficacy Scale (FES) (30), scored 0–100, with higher scores

representing greater fear of falling; participants were dichotomized as having a fear of falling during daily tasks (scores ≥70) (30).

Life-space: The UAB Study of Aging Life-Space Assessment (31) captures community mobility and social participation by measuring how far respondents go (from the bedroom to other rooms in the home to outside the home, neighborhood, and town), as well as how often respondents go to these spaces and with how much help, over the past 4 weeks. Overall scores range from 0 to 120, with higher scores representing greater life-space mobility.

Other Variables—Participants' perceived stress was assessed during the pilot study visit using the 14-item Perceived Stress Scale (PSS-14; range 0–56; higher scores indicating greater perceived stress) (32). SLE-related organ damage was assessed during the most recent GOAL assessment using the self-administered Brief Index of Lupus Damage (BILD; range 0–30; higher scores indicating greater levels of damage) (33, 34). Current SLE activity was assessed via the Systematic Lupus Activity Questionnaire (SLAQ; range 0–44; higher scores indicating greater SLE-related disease activity) (35) during the most recent GOAL assessment. Age at assessment, age at SLE diagnosis, sex, race, ethnicity, education, employment, marital status, social support, and height and weight [used to calculate BMI, categorized as obese (≥30 kg/m^2) or nonobese (<30 kg/m^2)] were self-reported. Participants also self-reported their relative health at the in-person assessment (five-point Likert scale; categorized as better than, same as, or worse than usual).

Statistical Analysis

Sociodemographic characteristics and self-reported health at assessment for APPEAL participants were summarized and compared with the overall GOAL cohort. Scores for physical and cognitive performance and self-reported functioning data were reported via means and percentages. Comparisons of scores across characteristics were tested via two-sample *t* tests, ANOVA, and Fisher's exact test. Stata v. 14.2 (StataCorp, College Station, TX) was used for all analyses.

Results

Study Population

Overall response rate was 56.1%. The mean age of the 60 participants in our pilot was 47.9 (50.0% and 23.3% were 40–59 and ≥60 years old); 90.0% were female, 80.0% were black, and most were non-Hispanic (Table 1). On average, participants had had SLE for 18 years, and most (86.7%) patients reported health as the same or better than usual on the day of their functional assessment. In general, distributions in our APPEAL pilot were similar to those seen in the most recent GOAL assessment (Table 1).

Physical Performance

The mean overall physical performance score was 8.8; while balance and gait speed had mean scores near the maximum value of 4, the mean lower body strength score was 1.8 (Figure 1). The balance, gait speed, and lower body strength tasks were not completed (due to participant inability or safety concerns; score=0) by 1.7%, 1.7% and 16.7% of the cohort,

respectively. Scores of <3 were obtained by 11.7%, 20.0%, and 70.0% of participants on the balance, gait speed, and lower body strength tasks, respectively; 71.7% scored <3 on at least one domain. There were no differences by age in balance scores; older participants had lower gait speed and lower body strength scores (not statistically significant; Figure S2). Male and white participants had higher gait speed and lower body strength scores than female and black participants, respectively. Participants with low vs. high disease damage and disease activity had higher gait speed, lower body strength, and overall physical performance scores; there were no differences in physical performance among obese vs. nonobese participants (Figure S2). The mean gait speed was 0.9 m/s. Those with higher (>median/≤median) self-reported physical functioning scores had higher physical performance scores: balance, 3.8 vs. 3.5, P=0.2; gait speed 3.9 vs. 2.8, P<0.001; and lower body strength, 2.6 vs. 0.9, P<0.001.

Cognitive Performance

Mean adjusted t-scores for cognitive performance (Figure 2) were average for episodic (47.7; 41st percentile) and working (48.6; 44th percentile) memory and low average for processing speed (42.6; 23rd percentile), cognitive flexibility (43.7; 27th percentile), and overall fluid cognition score (41.1; 19th percentile). The mean attention t-score (38.8; 13th percentile) was more than 1 SD below average for the general population. Among participants, 13.3%, 16.7%, 41.7%, 50.0%, 46.7%, and 43.3% had individual scores >1 SD below the mean on episodic memory, working memory, processing speed, attention, cognitive flexibility, and fluid cognition, respectively. There were few statistically significant differences in scores by participant characteristics (Figure S3). Adjusted t-scores were generally the same or higher for older vs. younger participants. In general, no substantial differences in t-scores by sex, race, disease damage, or perceived stress were noted, whereas obese participants had higher scores than nonobese participants on processing speed, attention, and overall fluid cognition (Figure S3). There were no differences in any cognitive domain by employment (*e.g.*, overall fluid cognition score, 41.2 vs. 40.9 for not employed vs. employed). Memory performance did not differ by self-reported forgetfulness (yes vs. no: episodic memory, 47.1 vs. 48.1; working memory, 48.8 vs. 48.8).

Self-Reported Functioning

Physical Functioning—The overall physical functioning score was 38.8 (Table 2). Scores were slightly lower in older vs. younger participants but substantially higher in male vs. female (46.7 vs. 37.9) and white vs. black (44.2 vs. 37.5) participants and, to a lesser extent, among participants with low vs. high disease damage and disease activity and nonobese vs. obese participants (Table S1).

Activities of Daily Living—In general, participants were more likely to report difficulties with IADLs vs. BADLs (Table 2). Most commonly, participants reported difficulty with shopping (41.7%), food preparation (35.0%), housework (13.3%), transportation (11.7%), bathing (13.3%), getting dressed (15.0%), and incontinence (20.0%; Table 2). Black vs. white participants were more likely to report difficulties with IADLs; no white participants reported difficulties with any BADL (Table S2). Difficulties with BADLs were more

commonly reported among obese vs. nonobese participants. Incontinence was most frequently reported among the youngest and oldest participants (Table S2).

Falls—Nearly half (45.0%) of participants reported falling in the prior year (Table 2). Falls were more frequently reported by female and black participants, as well those with high vs. low disease damage and activity and obese vs. nonobese participants (Table S3). FES scores were higher among black (25.8) vs. white (3.3) participants, as well as among those with high vs. low disease damage and activity. Overall, 8.3% had FES scores indicating a fear of falling (FES≥70) during daily tasks.

Life-Space Mobility—The average Life-Space Assessment score was 54.4 (Table 2). Scores were substantially higher for male (78.3 vs. 51.8) and white (79.9 vs. 48.1) participants as well as those with low disease activity scores (65.7 vs. 43.2); scores were similar by obesity and slightly higher among the oldest participants (51.6, 52.4, and 62.0 for those aged 20–39, 40–59, and ≥60; Table S4). While most participants are able to get outside their home without the assistance of another person, only 65.0% reported getting around their neighborhoods without personal assistance (Figure 3).

Discussion

In this cohort of SLE patients, we found substantial levels of potential impairment in both objective performance and self-reported functioning across multiple physical and cognitive domains, often similar to those seen in much older geriatric populations. For many domains, there was no clear association between older age and higher levels of impairment, despite the tendency for function to decline with age in the general population. While this may reflect the lack of validity of some of these measures in a non-geriatric SLE cohort, it may also reflect differences in the association of age with impairment in the setting of a chronic, inflammatory disease such as SLE or the inclusion of relatively high-functioning older adults in the SLE cohort. Furthermore, functioning did not always differ by disease activity and disease damage, suggesting that routine measures of disease activity may not capture the full range of physical or cognitive function among SLE patients. Of course, it is possible that impairment is primarily explained by SLE-related factors and we were underpowered to detect this effect or that SLE-related factors are incompletely captured by our measures of activity and damage. However, functioning differed by race, and these differences were often greater than those seen with disease activity and damage, suggesting that social factors may also contribute substantially to functional impairment in SLE.

We found that physical performance in this SLE cohort was comparable to or lower than that in the older adult population. The SPPB score cutoffs were chosen such that 50% of older adults (≥71 years old) scored ≥3 on the subscales (24); we found 88% and 80% achieved these scores for balance and gait speed, but only 30% of participants achieved these scores lower body strength. Importantly, the mean usual gait speed in our study (0.9 m/s) was substantially slower than that in a healthy population of volunteers aged 20–79 (1.3–1.5 m/s) (36). While scores for all subdomains were generally lower in older vs. younger study participants, the stronger correlates of poorer physical performance were black race, female sex, and higher disease-related damage and disease activity. Pain and inflammation due to

cumulative or current effects of SLE (*e.g.*, arthritis in lower limb joints) and/or even treatment-related muscle weakness (37) could explain the strikingly lower performance we observed for lower body strength relative to the other subdomains. In fact, 16.7% of our SLE cohort could not complete five chair stands, similar to the 21.6% of adults aged ≥71 years old who could not complete the task (24). Not surprisingly, self-rated physical functioning was also low in this population. The associations of lower self-rated physical functioning with female sex, black race, and higher disease-related damage and activity were similar to, but not as strong as, those of objective physical performance as measured by SPPB. Obesity was associated with poorer self-reported physical functioning but not with poorer physical performance. Given that we found a strong association (but not complete overlap) of physical performance and self-rated physical functioning and that SPPB scores have been found to predict poor outcomes (mortality and nursing home admission) even among older adults not self-reporting any disability (24), it may be important to assess both self-reported and objective physical performance in SLE patients of all ages.

Cognitive scores were average to low average. The domains with the lowest adjusted mean scores were attention (potential mild deficit), processing speed, and cognitive flexibility, and overall fluid cognition. Nearly half of participants had individual scores >1 SD below the mean for processing speed, attention, cognitive flexibility, and fluid cognition. Performance in these executive function domains is necessary for work productivity, particularly for jobs with a high cognitive requirement (38). This potential evidence of impairment may partially explain the substantial employment issues faced by SLE patients (39–41), although we did not detect any differences in cognitive performance by employment in this study. We found that, as expected, scores were not associated with age, sex, and race, given that the scores were adjusted for these characteristics. Adjusted scores were also not associated with disease damage and activity, and obesity was actually associated with higher scores on several cognitive subdomains. These results suggest the disease-related effects of SLE on cognitive function may be partially explained by demographic characteristics and social determinants of health (42). While forgetfulness was previously reported by nearly half of GOAL participants (18), we found that episodic and working memory scores in our ancillary pilot were close to average for the matched general population. Furthermore, although we previously found that perceived stress was strongly associated with higher prevalence of cognitive symptoms such as forgetfulness (18), associations between higher perceived stress and poorer cognitive performance on objective measures were of far lesser magnitude and not statistically significant. While Vogel *et al.* (10) also previously showed lack of agreement between subjective and objective measures of cognitive impairment in a Danish cohort, they found that complaints were less frequent than objective impairment; this discrepancy may reflect differences in culture, affective status of patients, coping skills, or cognitive assessments. As with physical functioning, perceived cognitive impairment may be as detrimental to overall health-related quality of life, employment, and social functioning (43) as objective impairment; thus, both self-reported and objective cognitive performance in SLE patients may be clinically relevant.

Other self-reported indicators of functioning may also provide essential information for the patient/caretaker, rheumatologist, and primary care provider. For example, inability to perform IADLs (28) generally precedes inability to perform BADLs (28). While the former

may indicate the need for frequent personal assistance, the latter may require full-time caretaking and/or institutionalization. As expected, we found that inability to independently perform IADLs was more prevalent than inability to independently perform BADLs. Problems with shopping (42%) and food preparation (35%) were most commonly reported, particularly in female and black participants. Despite evidence of potential problems with cognitive performance, only 3% of participants reported problems managing finances, and no participants reported problems managing medications. Although less common, problems with bathing (13%), dressing (15%), and transferring (8%) may reflect SLE-related arthritis. Incontinence was reported by 20% of the population. Whether this reflects bladder or bowel incontinence is unknown due to the nature of the question. Furthermore, high prevalence of incontinence regardless of age or sex and its observed association with SLE-related damage suggest that reported incontinence may be primarily disease- and/or treatment-related, rather than age- and/or sex-related (44).

Nearly half (45%) of our pilot participants reported falling in the prior year. While female and black participants were more likely to report falls than their male and white counterparts, these differences were not statistically significant; however, higher vs. lower disease-related damage and activity were associated with about twice the likelihood of reporting falls in the prior year. Given the high prevalence of falls in our cohort—much higher than the 25% reported for American adults aged ≥65 years (45)—in addition to the potential for injuries and fractures related to both recurrent falls and ongoing corticosteroid treatment, further research on the predisposing and precipitating factors contributing to falls in this population is necessary.

The oldest participants in our cohort (≥60 years) reported the highest Life-Space Assessment score (62.0; vs. 51.6 among those aged 20–39 years and 52.4 among those aged 40–59 years). In comparison, the mean score in the UAB Study of Aging population, in whom the instrument was developed and which included a diverse group of older adults (≥65 years) was 64.4 (31); the mean score in a population with advanced chronic kidney disease (mean age, 77 years) was 58.3 (46). Similarly to Peel *et al.* (31), we found that female and black participants had substantially lower scores than their participants; higher current disease-related activity (but not cumulative disease-related damage) was also associated with lower scores, suggesting modifiability via control of SLE. The extent to which other factors, such as depression, financial constraints, and safety concerns, might also contribute to these low scores is unknown. However, the low scores are striking in this relatively young population, with only 40% having unlimited mobility without assistance from another person. Because limited life-space mobility is associated with poor outcomes, including mortality (47), we need further exploration into the relevance of this geriatric measure in SLE.

Our study has several limitations not noted above. First, our pilot was inadequately powered to detect subgroup differences, adjust for confounders, and examine the overlap of these assessments. Second, while the pilot was representative of the parent GOAL cohort, the results may not be generalizable to SLE populations outside of metropolitan Atlanta, particularly to those that are not primarily black. Both the prevalence of potential functional impairments and their association with sociodemographic or clinical characteristics may differ in populations with different racial or ethnic composition than our pilot. Third,

misclassification by self-report is possible. Most of our respondents indicated that they were feeling the same or better than usual at study visit, which may have led to underreporting of impairment. Additionally, variables from the ongoing GOAL cohort may not always reflect the functional state of the participants at the APPEAL in-person assessment, since GOAL and APPEAL assessments were 6 months apart on average and functioning may fluctuate over time with SLE activity. Finally, the cognitive measures used are not diagnostic; identifying cognitive impairment requiring clinical intervention with these assessments is not possible.

Despite its limitations, to our knowledge, this hypothesis-generating study, performed in a representative sample from a diverse, population-based SLE cohort, provides a first look at several novel individual functional domains, as well as a simultaneous, multi-domain assessment of functioning in the setting of SLE. While the clinical ease and utility of geriatric functional assessment and potential clinical interventions remain unexplored in SLE, other specialties such as oncology (13, 14) and nephrology (48–50) are already exploring the value of geriatric assessment for improving risk stratification, developing individualized treatment plans, maximizing treatment adherence, and assessing the impact of disease-specific treatment on patient-reported outcomes. Our results suggest high prevalence of impairment across multiple domains of function in SLE patients of all ages, similar to or exceeding the prevalence seen in the general geriatric population. Several hypotheses suggested by our data—*e.g.*, that age is not predictor of functional impairment in the setting of SLE, that functional impairment is a result of SLE-related activity, and that social factors contribute substantially to impairment in this population—and even hypotheses involving factors that could not be fully examined in our data—*e.g.*, that inflammatory markers, muscle dysfunction, depression, and/or corticosteroid use explain the observed impairments—could be more thoroughly explored in future studies. Further research into the value of geriatric assessment in the setting of SLE is warranted.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Significance and Innovations

- While multi-domain functional assessment is commonly performed in geriatric patients to improve risk stratification, support self-management, and assess impact of treatments, it is novel among SLE patients
- In this pilot study of participants from an ongoing, diverse, population-based SLE cohort, we found high prevalence of impairment across multiple domains of function, similar to or exceeding the prevalence seen in much older geriatric populations
- Furthermore, prevalence of impairment was often as high in younger as it was in older participants
- Our results suggest that further research into the added value of geriatric assessments, including multi-domain functional assessment, in routine SLE care is warranted

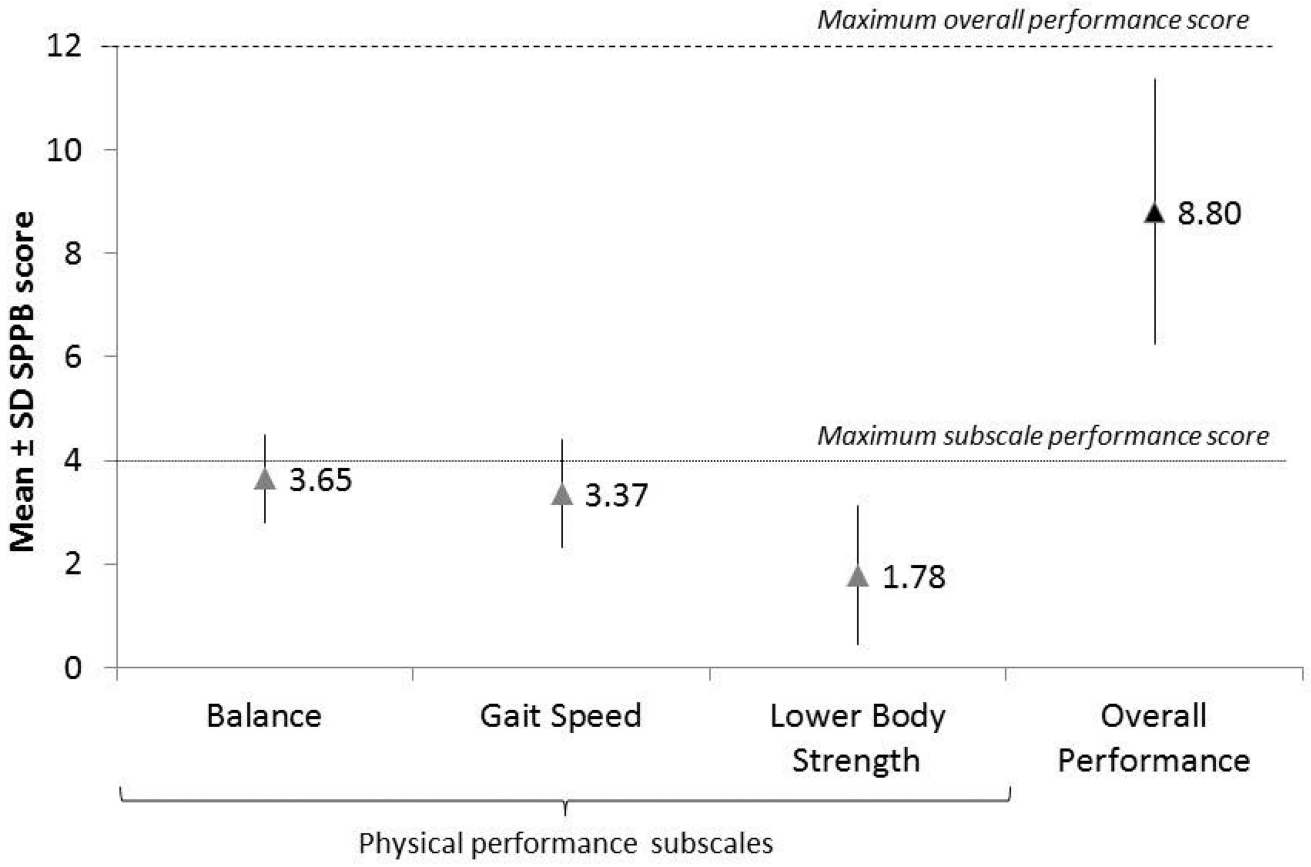

Figure 1.

Mean physical performance scores of 60 SLE patients, as measured by the Short Physical Performance Battery. Subscales (balance, gait speed, and lower body strength) have a range of 0–4, with 4 being the maximum/highest function (*dotted line*). The overall physical performance score is the sum of subscale scores and has a range of 0–12, with 12 being the maximum/highest possible performance (*dashed line*).

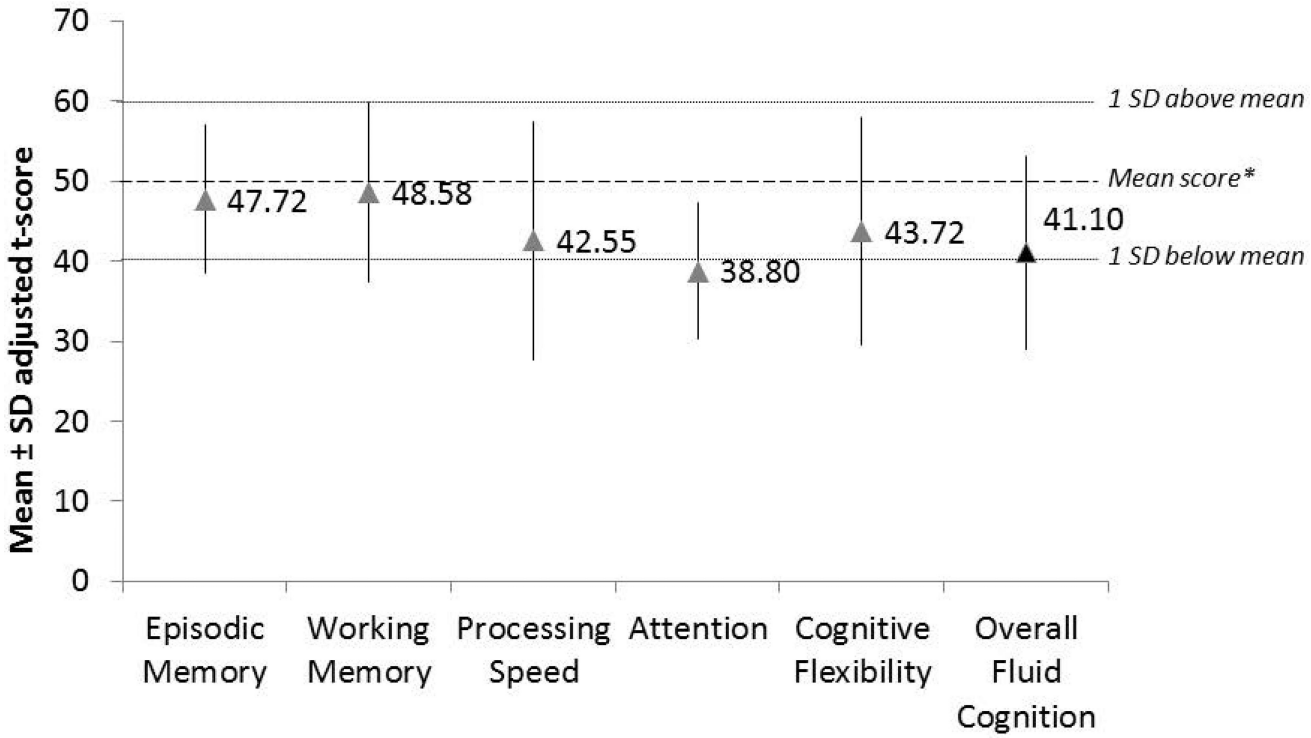

Figure 2.

Mean cognitive performance among 60 SLE patients, as measured by NIH Toolbox cognitive assessments. *Scores represent t-scores adjusted for age, race, ethnicity, and education level and are scaled 0–100, with 50 (*dashed line*) representing the average score. A 10-point increment = 1 SD, such that scores of 40 and 60 (*dotted lines*) = 1 SD below and above the mean score for the same age, race, ethnicity, and education level, respectively.

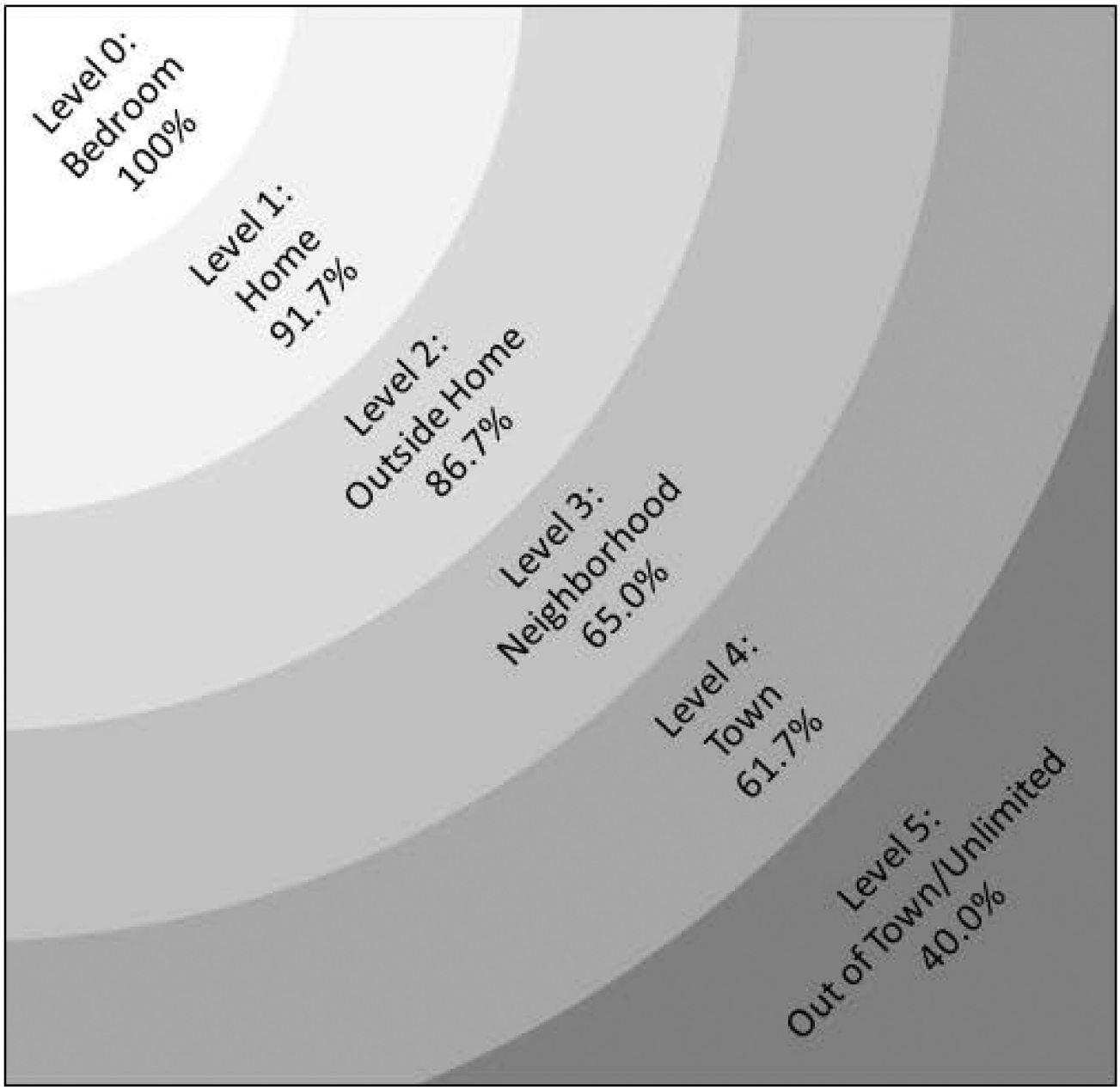

Figure 3.

Reported life-space mobility among 60 SLE patients, as measured by percentages of patients reporting ability to reach level without assistance from another person. Figure adapted from Peel *et al.* (30).

Table 1

Characteristics of SLE patients participating in the APPEAL ancillary pilot study (10/16–4/17) and in the parent GOAL cohort

Characteristic*	APPEAL Pilot	GOAL Cohort**
N	60	787
Sociodemographic		
Mean (SD) age, years	47.9 (12.6)	48.5 (13.8)
Age group, no. (%)		
20–39 years	16 (26.7)	243 (28.8)
40–59 years	30 (50.0)	399 (49.6)
60+ years	14 (23.3)	172 (21.6)
Sex, no. (%)		
Male	6 (10.0)	53 (6.7)
Female	54 (90.0)	734 (93.3)
Race, no. (%)		
White	12 (20.0)	132 (16.8)
Black	48 (80.0)	655 (83.2)
Ethnicity, no. (%)		
Hispanic	4 (6.7)	28 (3.6)
Non-Hispanic	56 (93.3)	754 (96.4)
No. years of education, no. (%)		
<16 years	32 (53.3)	501 (64.3)
≥16 years	28 (46.7)	278 (35.7)
Currently employed, no. (%)		
No	40 (66.7)	490 (62.3)
Yes	20 (33.3)	297 (37.7)
Psychosocial		
Median (IQR) PSS-14 score	24.0 (17.5–28.5)	---
Currently married/partner, no. (%)		
No	39 (67.2)	490 (62.6)
Yes	19 (32.8)	293 (37.4)
Current receiving social support, no. (%)		
No	25 (41.7)	438 (55.2)
Yes	35 (58.3)	355 (44.8)
Median (IQR) depressive symptom (PHQ) score	6.0 (3.0–9.0)	6.0 (2.0–11.0)
Mild/moderate/severe depression, no. (%)	38 (63.3)	483 (61.4)
Clinical		
Median (IQR) disease damage (BILD) score	3.0 (1.0–5.0)	3.0 (1.0–4.0)
Median (IQR) disease activity (SLAQ) score	16.5 (12.0–22.0)	15.0 (9.092013;22.0)
Mean (SD) age at diagnosis, years	30.2 (12.0)	32.7 (12.0)
Mean (SD) disease duration, years	17.7 (10.9)	15.9 (10.2)
Obesity (BMI≥30 kg/m^2) (%)	23 (39.0)	330 (43.2)

Characteristic*	APPEAL Pilot	GOAL Cohort**
Self-reported health at assessment, no. (%)		
Better than usual	21 (35.0)	---
Same	31 (51.7)	---
Worse than usual	8 (13.3)	---

PSS-14, 14-item Cohen's Perceived Stress Scale score (possible score range=0–56, with higher scores indicating greater stress); PHQ, Patient Health Questionnaire (range 0–27 with higher scores indicating more severe depression; >5 mild/moderate/severe depression); BILD, Brief Index of Lupus Damage (range, 0–30, with higher scores indicating greater levels of damage); SLAQ, Systemic Lupus Activity Questionnaire (range, 0–44 with higher scores indicating greater SLE-related disease activity). *N*=60 for all variables in the APPEAL pilot except marital status (*n*=58) and obesity (*n*=59).

*Collected at APPEAL visit (age, sex, race, ethnicity, education, PSS-14 scores, self-reported health at assessment) or during GOAL assessment (mean time from GOAL to APPEAL visit, 176 days).

**White and black participants who completed most recent GOAL assessment (6/16–1/17), including those who participated in APPEAL.

Table 2

Self-reported functioning among 60 SLE patients, over multiple domains.

Measure	Mean (SD) or no. (%)
Physical functioning	
Mean (SD) PF-12 t-score	38.8 (10.9)
Instrumental activities of daily living	
No. (%) reporting difficulty with:	
Using telephone	0 (0.0%)
Shopping	25 (41.7%)
Food preparation	21 (35.0%)
Housework	8 (13.3%)
Laundry	2 (3.3%)
Transportation	7 (11.7%)
Managing finances	2 (3.3%)
Managing medications	0 (0.0%)
Basic activities of daily living	
No. (%) reporting difficulty with:	
Bathing	8 (13.3%)
Dressing	9 (15.0%)
Toileting	1 (1.7%)
Transferring	5 (8.3%)
Feeding self	0 (0.0%)
Incontinence	12 (20.0%)
Falls	
No. (%) with falls in prior year	27 (45.0%)
Mean (SD) number of falls in prior year	0.93 (1.18)
Mean (SD) FES score (scale 0–100)	25.2 (23.9)
No. (%) with fear of falling (FES≥70)	5 (8.3%)
Life-space mobility	
Mean LSA score (scale 0–120)	54.4 (34.4)

PF-12, 12-item PROMIS physical functioning assessment (higher scores=better physical functioning, actual range of t-scores = 13.3–66.1); FES, Falls Efficacy Scale (higher scores=greater fear of falling during daily tasks); LSA, Life-Space Assessment (higher scores=greater life-space mobility).