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Limitations in Activities of Daily Living among Individuals with Systemic Lupus Erythematosus

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Abstract

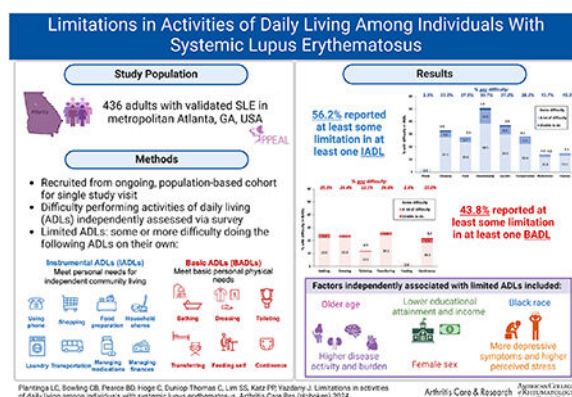
Objective: We aimed to estimate the burden and identify potential correlates of limitations in activities of daily living (ADLs) among persons with systemic lupus erythematosus (SLE).

Methods: Individuals with SLE were recruited from a population-based cohort (10/2019–5/2022) and reported their ability to independently perform various instrumental ADLs (IADLs) and basic ADLs (BADLs) via survey. Limitations were defined as having at least some difficulty performing at least one of the IADLs or BADLs. Descriptive statistics were calculated, and associations [adjusted odds ratios (aORs)] of various participant characteristics with IADL and BADL limitations were assessed with logistic regression adjusting for age, sex, and race.

Results: The mean age of the 436 participants was 46.2 years; most were female (91.7%) and Black (82.8%). More than half (56.2%) reported limitations in IADLs, most commonly housekeeping (50.7%), laundry (37.2%), and shopping (33.0%); 43.8% reported limitations in independently performing BADLs, most commonly transferring (26.6%), bathing (25.3%), dressing (24.4%), and continence (22.0%). Higher disease activity ($\geq$ vs. $<$ median) was most strongly associated with IADLs (aOR=6.49, 95% CI 4.15–10.2) and BADLs (aOR=7.35, 95% CI 4.70–11.5), along with higher depression and perceived stress scores; lower educational attainment and income; and older age.

Conclusion: IADL and BADL limitations may be common in SLE and more prevalent among those who report higher disease activity, depressive symptoms, and lower income and among those who are older. Research to support evidence-based strategies for improvement in quality of life and maintenance of independence in the aging SLE population is warranted.

Graphical Abstract



Introduction

With increasing life expectancy among those with systemic lupus erythematosus (SLE),¹ a primary goal of SLE providers should be maintaining patient independence among their patients as they age. To address this, we first need to understand the current state of limitations in the essential, routine tasks known as activities of daily living (ADLs) among an aging population with SLE and the factors associated with these limitations. ADLs include instrumental ADLs (IADLs), which meet personal needs for independent community living (*e.g.*, food preparation and household chores),² and basic ADLs (BADLs), which meet basic personal physical needs (*e.g.*, bathing and dressing)³; limitations in either can lead to poor quality of life and loss of independence.

ADL limitations are most frequently associated with older populations. However, in 2019, 6% of U.S. adults aged 18–64 years reported a lot of difficulty or inability to perform in at least one functional domain, and these limitations were more common among those who were Black (7%) or living below the poverty level (15%).⁴ Further, for those with chronic conditions, such as arthritis, the prevalence of ADL limitations can be much higher, regardless of age.⁵ Given that the population with SLE is disproportionately underserved and socioeconomically disadvantaged — and that SLE is a complex, chronic, and heterogeneous disease — understanding the prevalence of and factors associated with IADL and BADL limitations in these patients is even more important for maximizing independence and minimizing disability.

While there is some evidence suggesting that ADL limitations may be highly prevalent in SLE,^{6,7} less is known about the specific measures of IADLs and BADLs in SLE. To address this gap, we sought to characterize the burden and correlates of limitations in IADLs and BADLs in a population-based cohort of individuals with SLE.

Methods

Study Population and Data Sources

The Approaches to Positive, Patient-centered Experiences of Aging with Lupus (APPEAL) study recruited participants with validated SLE⁸ from the population-based Georgians Organized Against Lupus (GOAL) cohort in metropolitan Atlanta,^{9,10} with exclusions for

being inactive in GOAL, being unable to speak English, having insufficient vision and hearing to undergo study testing, being unable to consent, or living outside of Georgia at the time of recruitment. The Emory Institutional Review Board approved the APPEAL (IRB00110977) and GOAL (IRB00003656) study protocols. APPEAL participants provided informed consent before completing study visits.

A total of 451 participants completed the APPEAL study visit between 10/8/2019 and 5/12/2022. For this analysis, we excluded participants whose overall survey response patterns were potentially invalid ($n=4$) or who did not have complete IADL and BADL assessments ($n=11$). Study data were obtained from performance tests and self-administered questionnaires and additionally linked to data from the GOAL survey closest to the APPEAL visit date.

Variables

Limitations in ADLs.—Participants were asked about their limitations in the following IADLs²: using the phone, shopping, food preparation, housekeeping, laundry, transportation, managing medications, and managing finances (Table 1). BADLs³ assessed included bathing, dressing, toileting, transferring, feeding, and continence (Table 1). For primary analyses, IADL and BADL limitations were defined as any difficulty (some or more difficulty) vs. no difficulty performing at least one of the IADL and BADL tasks independently.

Other variables.—Sociodemographics included age, sex (at birth), race, ethnicity, and education, all self-reported by the participant via the NIH Toolbox from a fixed set of categories. Race was categorized as Black (single or multiple race), other, and White. Education was the highest level attained and categorized as high school graduate/equivalency or lower, some college/associates degree, and college graduate or higher. Current working status was assessed with the Work Productivity and Activity Impairment Questionnaire.^{11–13} Current income (categorized as <\$20,000, \$20,000–59,999, and ≥\$60,000), receipt of Social Security disability benefits, and disease duration (adjusted for the date of the APPEAL visit) were self-reported at the closest GOAL assessment. Current SLE activity was assessed via the Systematic Lupus Activity Questionnaire (SLAQ; range 0–44; higher scores indicating greater SLE-related disease activity).¹⁴ The Brief Index of Lupus Damage (BILD) score (range, 0–46; higher scores indicate greater cumulative SLE-related organ damage)^{15,16} was obtained from linked GOAL data. Cumulative damage to individual systems was defined by BILD items, as were comorbid heart, cerebrovascular, and pulmonary disease. Current steroid use was self-reported by the participant at the study visit. Body mass index (BMI) was calculated from height and weight; obesity was defined as BMI ≥ 30 kg/m². Physical activity was assessed with the International Physical Activity Questionnaire – Short Form.¹⁷ Depressive symptoms were assessed via the validated 8-item PROMIS Depression Short Form-8a (T-scores; mean=50, SD=10).^{18,19} Finally, perceived stress was assessed using the 10-item Perceived Stress Scale (PSS-10) (range 0–40; higher scores indicate greater perceived stress).^{20,21} Other potential indicators of disability included: physical performance [Short Physical Performance Battery (range, 0–12; higher scores=better performance)]^{22,23}; physical functioning T-score [PROMIS Physical

Functioning-Short Form 12a with (mean=50, SD=10; higher scores=better functioning)]²⁴; composite age-corrected standard fluid cognition score [NIH Toolbox Fluid Cognition Battery (mean=100, SD=15; higher scores=better performance)]^{25–28}; and community mobility score [UAB Study of Aging Life-Space Assessment (range, 0–120; higher scores=greater community mobility)].²⁹

Statistical Analysis

Characteristics of participants were described overall, and percentages with limitations in IADLs and BADLs were described overall and by selected participant characteristics. Patterns in limitations were explored using Venn diagrams and UpSet plots. Adjusted ORs (aORs) for associations of any limitation in IADLs or BADLs with selected characteristics were obtained with multivariable logistic regression, adjusting for demographics (age, sex, and race). In sensitivity and additional analyses, we explored: (i) associations of IADL and BADL limitations with characteristics, with additional adjustment for socioeconomic indicators (education and income), SLE-related factors (SLAQ and BILD scores), and comorbid conditions (heart, cerebrovascular, and pulmonary disease); (ii) associations of IADL and BADL limitations with characteristics among subgroups of those not receiving disability benefits, those who were Black, and those who were White; (iii) associations of IADL and BADL limitations with individual disease damage domains; (iv) numbers of limitation in IADLs and BADLs, defined as the number of individual tasks in which individuals reported at least some difficulty; (v) severe limitations in IADLs and BADLs, defined as reporting a lot of difficulty with or being unable to do at least one of the IADL or BADL tasks, respectively; and (vi) limitations in individual IADL and BADL tasks. Complete case analysis was used. All analyses (statistical significance threshold=0.05) were conducted using Stata v. 18.5 (College Station, TX).

Results

Characteristics of Study Participants

Study participants ($N=436$) had a mean age of 46.2; 41.3% were ≥ 50 years old (Table 2). Most were female (91.7%), Black (82.8%), and non-Hispanic (94.5%). About one-quarter (23.4%) had a high school degree or less, and 35.2% had an annual household income of less than \$20,000. Nearly half (44.9%) reported receiving disability benefits. The median duration of SLE was 14.8 years, with median SLAQ and BILD scores of 11 and 2, respectively. Cumulative SLE damage was most frequently reported for the ocular (30.7%), cardiovascular (24.3%), and peripheral vascular and musculoskeletal (19.7% each) systems. About half (47.5%) were obese, and 73.7% reported low physical activity (Table 2).

Reported Limitations in Activities of Daily Living among Individuals with SLE

More than half reported at least some limitation in at least one IADL ($n=245$, 56.2%), while 43.8% ($n=191$) reported at least some limitation in at least one BADL. Most individuals (79.4%) were concordant in their limitations: 39.6% reported no limitations in either IADLs or BADLs, and 39.6% reported limitations in both; however, 16.6% had IADL limitations without BADL limitations and 4.2% had BADL limitations without IADL limitations (Figure 1).

Overall, 43.8%, 9.4%, 9.6%, and 37.2% had limitations in zero, one, two, or three or more IADL tasks (Figure 2). Among those with any IADL limitations, 16.7%, 17.1%, and 66.2% had limitations in one, two, or three or more tasks. For BADLs, 56.2%, 16.5%, 7.6%, and 19.7% had limitations in zero, one, two, or three or more tasks (Figure 2); for those with any BADL limitation, 37.7%, 17.3%, and 45.0% had limitations in one, two, or three or more tasks. The numbers of IADL and BADL limitations were strongly positively correlated with each other ($\rho=0.74$) and strongly negatively correlated with physical functioning ($\rho=-0.70$ for IADL and $\rho=-0.64$ for BADL limitations), while correlations of these limitations with physical and cognitive performance, receipt of disability benefits, and community mobility were low to moderate (Supplementary Table 1). Severe limitations (a lot of difficulty with or inability to do any of the tasks) in IADLs and BADLs were seen in 16.3% and 7.8%, respectively, and severe limitations in both IADLs and BADLs were seen in 5.3%.

The prevalence of ADL limitation varied widely by individual task. Among the IADLs (Figure 3A), limitation prevalence ranged from 2.5% (using the phone) to 50.7% (housekeeping); about one-third each reported limitations in shopping (33.0%) and doing laundry (37.2%). Among the BADLs (Figure 3B), limitation prevalence ranged from 2.8% (feeding) to 26.6% (transferring); about one-quarter each reported limitations in bathing (25.3%), dressing (24.4%), and continence (22.0%). Most with limitations reported some difficulty for each of the tasks (Figure 3). The most common patterns of limitations among those with any IADL limitations were in housekeeping only (11.8%) and in housekeeping, preparing food, shopping, doing laundry, and transportation (11.8%) (Supplementary Figure 1A). The most common patterns of limitations among those with any BADL limitations were in continence only (19.4%) and in bathing, dressing, toileting, and transferring (10.5%) (Supplementary Figure 1B).

Factors Associated with Limitations in Activities of Daily Living

Prevalence of any IADL limitation was higher in older participants (59.4% vs. 45.4% in those aged ≥ 50 vs. 18–34). After adjustment for sex and race, age ≥ 50 vs. 18–34 years was associated with 78% higher prevalence odds (Table 3); this association was consistent with further adjustment but was not statistically significant after adjustment for SLAQ and BILD scores (Supplementary Table 2). While IADL limitations were more prevalent in female vs. male (57.3% vs. 44.4%) and Black vs. White (57.6% vs. 47.1%) participants, the differences were not statistically significant (Table 3); the associations for Black vs. White race were null after adjustment for education and income (Supplementary Table 2). Lower educational attainment was also associated with higher prevalence of IADL limitations, with 2.2- and 1.8-fold higher adjusted prevalence odds for those with high school or less and some college, vs. being a college graduate (Table 3), but the associations were attenuated after adjustment for socioeconomic factors (Supplementary Table 2). Lower income levels ($< \$20,000$ and $\$20,000$ – $59,999$, vs. $\geq \$60,000$) were associated with 3.2- and 2.1-fold higher odds of IADL limitations and were consistent with adjustment. Receipt of disability benefits was associated with 3.5-fold higher odds of limitations in IADLs (Table 2); further, of those with any IADL limitations, 58.0% were receiving disability benefits (Figure 1). Higher scores for disease activity (SLAQ; 6.5-fold), depression (3.4-fold), perceived stress (2.7-fold), and disease damage (BILD; 1.8-fold) were all associated with higher odds of IADL

limitations (Table 3); only higher disease activity and higher depressive symptom scores remained statistically significantly associated with IADL limitations after further adjustment for socioeconomic and SLE-related factors and comorbid conditions (Supplementary Table 2). High and moderate vs. low physical activity were associated with 60% and 79% lower odds of IADL limitations. Current steroid use and obesity were not associated with prevalence of IADL limitations (Table 3). While underweight status ($<18.5 \text{ kg/m}^2$) was associated with higher odds of limitations (unadjusted OR=2.05, 95% CI 0.61–6.85) in separate analyses, the results were not statistically significant. Subgroup analyses showed that associations were similar in those not receiving disability benefits, with slightly stronger effects for lower income, higher disease activity, and higher perceived stress; there were no notable differences between those who were Black and White, except the association of disease damage with IADL limitations was stronger in the White (aOR=6.79, 95% CI 1.80–25.7) vs. Black (1.54, 95% CI 1.00–2.37) participants (P for interaction=0.04; Supplementary Table 3). Neuropsychiatric (3.0-fold), pulmonary (2.2-fold), cardiovascular (1.9-fold), and peripheral vascular (1.9-fold) damage were all associated with higher odds of IADL limitations, while the association of musculoskeletal damage with higher odds of IADL limitations (1.6-fold) was not statistically significant (Supplementary Table 4).

BADL limitations were less frequently reported, but associations of these limitations with characteristics were similar to those seen with IADL limitations. For example, prevalence of any BADL limitation was higher in older participants (47.8% vs. 31.8% in those aged ≥ 50 vs. 18–34); after adjustment for sex and race, age ≥ 50 vs. 18–34 years was associated with 1.9-fold higher prevalence odds (Table 3); this association was consistent with further adjustment (Supplementary Table 5). Lower educational attainment and lower income were also associated with higher odds of BADL limitations. Unlike IADLs, White vs. Black race was associated with 51% lower odds of BADL limitations (Table 3), but this association was attenuated after adjustment for socioeconomic factors (Supplementary Table 5). Receipt of disability benefits was associated with 3.1-fold higher odds of limitations in BADLs (Table 3), with 61.4% of those with IADL impairments receiving disability benefits (Figure 1). As with IADL limitations, higher scores for disease activity (7.4-fold), depression (3.0-fold), perceived stress (2.5-fold), and disease damage (1.7-fold) were all associated with higher odds of BADL limitations, while high and moderate vs. low physical activity were associated with 52% and 75% lower odds of BADL limitations (Table 3); the associations of oldest vs. youngest age, higher disease activity, higher depressive symptom scores, and high vs. low physical activity all remained statistically significant after full adjustment (Supplementary Table 5). Current steroid use and obesity were not associated with prevalence of BADL limitations (Table 3), nor was underweight status in separate analyses. Associations were similar among those not receiving disability benefits and between those who were Black vs. White (Supplementary Table 6). Neuropsychiatric (2.5-fold), pulmonary (2.4-fold), peripheral vascular (1.9-fold), and musculoskeletal (1.7-fold) damage were all associated with higher prevalence of BADL limitations (Supplementary Table 4).

The number of tasks in which there were limitations also differed by characteristic (Supplementary Tables 7 and 8). Black participants were more likely than White participants to report three or more IADL task limitations (41.3% vs. 19.6%; Supplementary Table 7)

or three or more BADL task limitations (22.7% vs. 5.9%; Supplementary Table 8). Those with high school degrees or less or some college also more likely to report three or more IADL limitations (44.1% and 44.5% vs. 25.9%) or three or more BADL limitations (25.5% and 25.0% vs. 11.2%) than those who graduated college, as were those with lower vs. highest income (52.4% and 33.9% vs. 20.8%; and 28.2% and 19.1% vs. 7.6%, respectively). Those with higher scores for disease activity, disease damage, depression, and perceived stress also had statistically significantly higher prevalence of greater numbers of limitations (Supplementary Tables 7 and 8). Severe limitations in IADLs and BADLs, while less frequent than any limitations, followed similar patterns of associations with characteristics (Supplementary Table 9).

Participant characteristics were also associated with individual IADLs (Supplementary Table 10) and BADLs (Supplementary Table 11) tasks. For example, older age was associated with higher prevalence of limitations in using the phone, food preparation, housekeeping, doing laundry, and managing finances, while Black vs. white race was associated with higher prevalence of limitations in shopping, food preparation, doing laundry, and transportation (Supplementary Table 10). Lower income, higher disease activity, and higher scores for depression and perceived stress were associated with higher prevalence of limitations in most IADL tasks (Supplementary Table 10). Except for continence, older age was not associated with a higher prevalence of limitations in individual BADL tasks, while the Black vs. White race was associated with a higher prevalence of limitations in bathing, toileting, and transferring (Supplementary Table 11). Higher disease activity and perceived stress were both associated with higher prevalence of limitations in all BADL tasks (Supplementary Table 11).

Discussion

In this population-based SLE cohort, we found that more than half (56%) and nearly half (44%) reported limitations in independently performing at least one IADL and BADL, respectively. Additionally, limitations in multiple tasks were common: 37% and 66% of those with any limitations in IADLs and BADLs had limitations in three or more of the tasks. Further, while most of the reported limitations might be considered mild or moderate (with participants reporting some difficulty), 16% and 8% reported severe limitations in performing at least one IADL or BADL.

While data on the prevalence of IADL and BADL difficulty are sparse in the setting of SLE, we can make indirect comparisons of our estimates to the general adult population. For example, 6% of the 2019 U.S. adult population (18–64 years) reported severe limitations in at least one ADL, well below our prevalence of severe limitations (16% and 8% for IADLs and ADLs, respectively); in fact, our estimates were more similar to the prevalence in those aged ≥65–74 years (19%).⁴ Among adults aged ≥60 years in the National Health and Nutrition Examination Survey (NHANES) 2011–2018, any IADL limitation (some or more difficulty in managing medications, doing household chores, or food preparation) and any BADL limitation (some or more difficulty eating, dressing, getting in and out of bed, or walking between rooms) were reported by 28% and 21%, respectively³⁰; in a slightly younger population (2018 Health and Retirement Study participants aged ≥50 years), 17%

reported any BADL limitations.³¹ These estimates, using definitions similar to our primary analyses, all fall well below our estimates of 56% and 44% in our younger population. Further, our prevalence estimates for IADL and BADL limitations were lower than those among middle-aged (50–64 years) adults (NHANES 2011–2014) with congestive heart failure (58% and 56%) but were comparable to, or higher than, those for stroke (52% and 53%), cardiovascular disease (43% and 40%), chronic obstructive pulmonary disease (40% and 35%), arthritis (37% and 36%), chronic kidney disease (30% and 29%), and cancer (31% and 26%).³² Together, our results suggest that adults with SLE may experience more difficulty with both IADLs and BADLs than similarly aged and older adults and adults with other common chronic diseases.

In the setting of aging, we generally consider limitations in IADLs (tasks that foster independent living) to precede limitations in BADLs (tasks for basic self-care). Here, we found that 17% had IADL limitations only and 40% reported limitations in both IADLs and BADLs, suggesting that some individuals with SLE may have lived with unrecognized or unaddressed IADL limitations for some time before the development of BADL limitations. Alternatively, the same underlying issues (*e.g.*, profound fatigue) might have led to the simultaneous development of IADL and BADL limitations. Overall, these patterns suggest that the conceptualization of aging-related gradual loss of ability to perform IADLs independently, followed in time by limitations in BADLs, may not apply in the setting of SLE.

Certain IADL and BADL tasks were more frequently affected in our population. For IADLs, more than half (51%) reported limitations in doing household chores independently. Other common limitations were also in tasks that require both physical and cognitive labor: laundry (37%), shopping (33%), transportation (28%), and food preparation (28%), and these limitations often clustered together within individuals. Limitations in IADLs that arguably require primarily cognitive labor — managing medications (14%) and finances (15%) and using the phone (3%) — were less commonly reported. Within the BADLs, reported limitations in transferring (27%), bathing (25%), and dressing (24%) were common, perhaps partially reflecting mobility issues, while limitations in feeding (3%) were rarely reported. Surprisingly, limitations in continence were commonly reported (22%; 23% of women and 13% of men), and the most common pattern of BADL limitations seen in our population was limited continence alone. For comparison, 28% and 14% of women and men aged ≥ 50 years in NHANES reported some level of either urinary or fecal incontinence.³³ Limitations in getting on and off the toilet were less common (12%), suggesting that limitations in continence may be more related to bladder symptoms than functional limitations that interfere with toileting. Further epidemiologic exploration of incontinence in SLE is warranted.

While older age was associated with higher prevalence of limitations in IADLs and BADLs in our cohort, as expected, several other factors were strongly associated with these limitations. Higher disease activity was associated with ~ 7 -fold higher odds of both IADL and BADL limitations. Related variables, including scores for depression and perceived stress, were also associated with substantially higher odds of these limitations. Lower educational attainment and income, but not sex or race, were generally statistically

significantly associated with higher odds of limitations. However, White vs. Black race was associated with 50% lower odds of BADL limitations only. Higher physical activity was associated with lower odds of limitations, while obesity was not associated with IADL or BADL limitations. Overall, these results suggest that observed limitations in ADLs among those with SLE may be driven by emotional functioning as much as by physical and cognitive functioning. Interestingly, the receipt of disability benefits was associated with higher odds of limitations, as expected, but the overlap of these limitations with receipt of disability benefits was far from complete: 42% and 39% of those with IADL and BADL limitations were not receiving disability benefits, and 23% of those receiving disability benefits had no ADL limitations. Further, associations of characteristics with IADL and BADL limitations among those who were not receiving benefits were similar to those in the overall cohort.

Of course, BADLs and IADLs are imperfect measures of limitations. IADLs and BADLs do not measure individuals' value for being able to perform the task. The Valued Life Activities (VLA) measure accounts for both the ability to perform an activity and the importance that the respondent places on the activity. Using the VLA, Katz *et al.*⁷ found that most (91%) of their cohort (>800 individuals) had at least one VLA that was affected by their SLE, and VLA disability was associated with 4-fold higher odds of fair or poor self-rated health.⁶ Additionally, the measured tasks may differ across individuals. For example, limitations in laundry may be more likely for people who need to go to a laundromat or navigate stairs with laundry. Similarly, limitations in transportation may depend on whether an individual has a car or whether public transportation is available, adequate, and easy to use. Our results showing that income was associated with higher odds of IADL limitations support the potential for increased difficulty of tasks in the setting of fewer resources. Finally, at least one IADL task — using the phone — may be outdated. This task originally captured the ability to hear the phone ringing and get to the phone in time to answer it, as well as dialing, remembering phone numbers, and standing for long periods while speaking. Now it is likely that limitations in using the phone reflect cognitive issues that make it difficult to navigate complex modern phones or issues with vision.

Other potential limitations of our study deserve mention. First, causal inference is limited in this cross-sectional study, and factors associated with limitations cannot be considered definitive risk factors. For example, limitations in ADLs might lead to reductions in income, rather than, or in addition to, low income creating or exacerbating ADL limitations. Second, while our cohort was population-based, it might not represent individuals with SLE in other geographic regions. Further, the participants we recruited into APPEAL may have represented a group with fewer IADL and BADL limitations than the GOAL cohort or even the general SLE population in metropolitan Atlanta, which would suggest we may be underestimating the true prevalence of ADL limitations. Third, although we had data from a large cohort, there was likely a lack of power in certain small subgroups (*e.g.*, subgroups of White participants), which limited our ability to examine stratified analyses and interaction terms. Finally, there are other unmeasured individual factors that might be important for IADL and BADL limitations, particularly, fatigue and sleep quality. In this study of patient-reported measures, we also did not have an objective measure of disease activity, such as the SLE disease activity index (SLEDAI-2K).³⁴ While we adjusted

for comorbid conditions extracted from the BILD score, these represent only severe and SLE-related damage; thus, there is likely suboptimal capture of comorbidity. Because we did not administer the Stanford Health Assessment Questionnaire Disability Index,³⁵ we cannot compare our results to those obtained with this more clinically used instrument. Information on environmental or household factors might also contribute to individuals' experiences of limitations: *e.g.*, presence of ramps, wide aisles, and accessible parking, along with availability and affordability of delivery or pick-up services, could support independent shopping; and walk-in access, bars, and/or seats in the shower could support independent bathing.

Our results suggest that limitations in both IADLs and BADLs are common in SLE. This burden may match or exceed the burden among older adults and those with other chronic diseases. ADL limitations may be more likely among those who report more SLE activity, depressive symptoms, and perceived stress, in addition to those who are older. Further study on the risk factors and outcomes of ADL limitations, as well as specific barriers and facilitators to performing IADLs and BADLs in the setting of SLE, are warranted. Such research will inform evidence-based strategies for improvement in quality of life and maintenance of independence in the aging SLE population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Significance and Innovations

- Maintaining patients' independence should be a priority for SLE providers with increasing numbers of SLE patients who are older
- We sought to understand the current state of activity limitations among the aging population with SLE and the factors associated with these limitations by exploring instrumental activities of daily living (IADLs, or tasks to support independent community living) and basic activities of daily living (BADLs, or tasks to support personal care) among a population-based cohort of primarily Black and female individuals with SLE
- We found that IADL and BADL limitations were common (56% and 44% reporting at least some difficulty, respectively) and that these limitations were more likely among those who were older and those who reported higher disease activity, depressive symptoms, and lower income
- Future research to develop and implement targeted interventions to maintain independence among individuals with SLE as they age is warranted

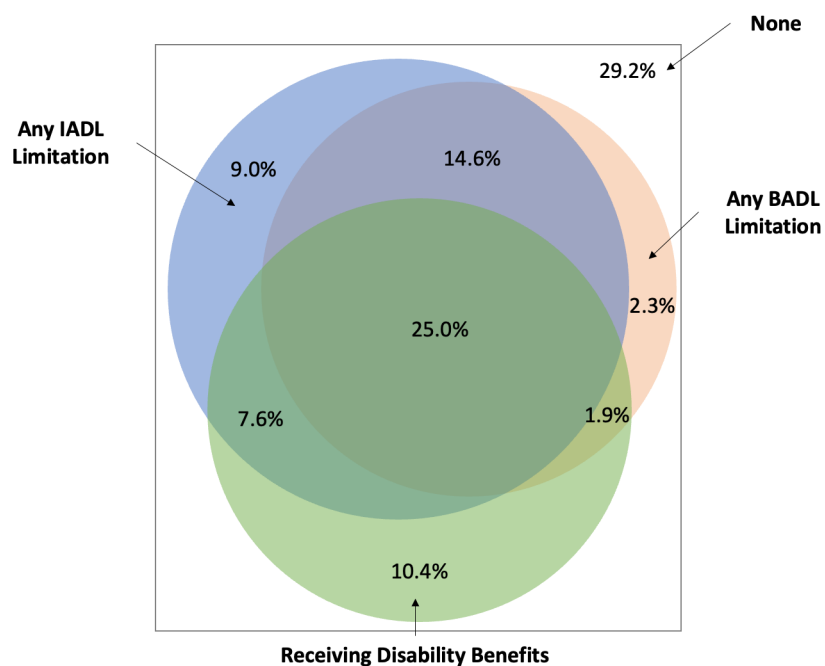


Figure 1. Venn diagram showing overlap of any limitation in instrumental activities of daily living, any limitation in basic activities of daily living, and self-reported receipt of disability benefits among individuals with systemic lupus erythematosus. BADL, basic activity of daily living; IADL, instrumental activity of daily living.

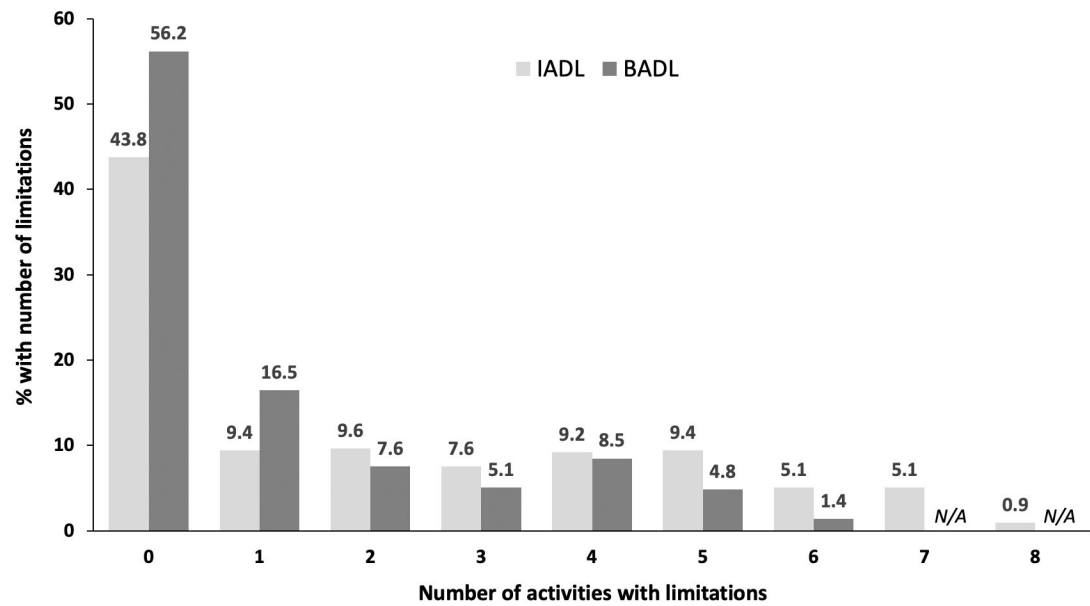


Figure 2.

Distribution of numbers of limitations in instrumental and basic activities of daily living among individuals with systemic lupus erythematosus.

BADL, basic activity of daily living; IADL, instrumental activity of daily living.

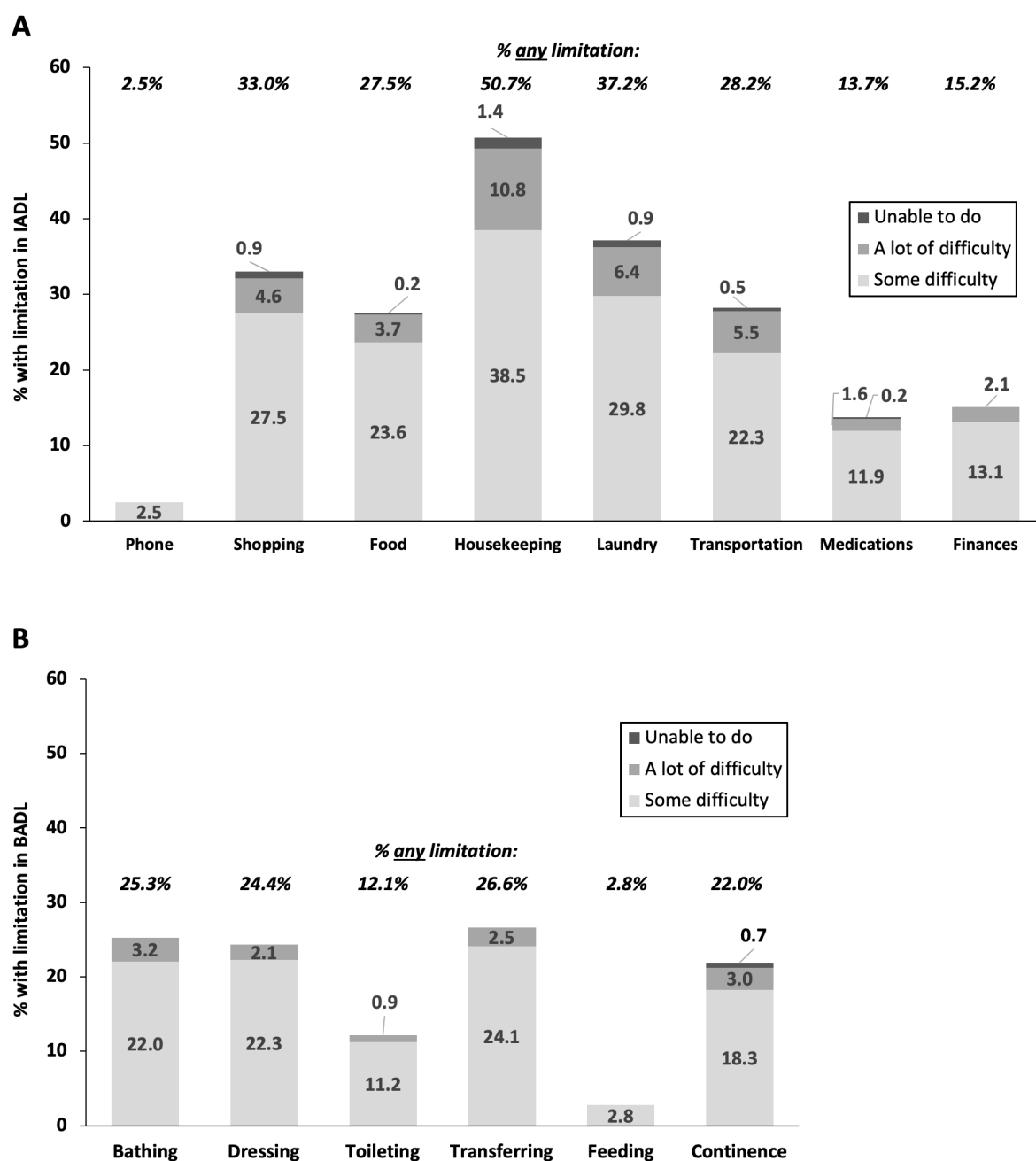


Figure 3. Percentage of individuals with SLE with limitations in instrumental (A) and basic (B) activities of daily living. Stacked bars, percentages within each level of difficulty (some difficulty, a lot of difficulty, and cannot do); overall percentages with any difficulty are shown above the stacked bars. BADL, basic activity of daily living; IADL, instrumental activity of daily living.

Table 1.

Study assessment of basic and instrumental activities of daily living

Domain/measure	Wording of item
Overall question:	How much difficulty do you have doing the following activities on your own?
<u>Possible responses:</u>	No difficulty
	Some difficulty
	A lot of difficulty
	Unable to do
	Could do it, but don't ^a
	Don't know or refuse ^b
<u>IADLs</u>	
Phone	Using the phone
Shopping	Shopping
Food	Preparing food
Housekeeping	Housekeeping
Laundry	Laundry
Transportation	Traveling (car, taxi, public transportation)
Medications	Managing your medications
Finances	Managing your finances
<u>BADLs</u>	
Bathing	Bathing or showering
Dressing	Getting dressed
Toileting	Using the toilet
Transferring	Moving in and out of bed and chairs
Feeding	Feeding yourself
Continence	Controlling your bowel and/or bladder

BADL, basic activity of daily living; IADL, instrumental activity of daily living.

^aTreated as "no difficulty."^bTreated as missing.

Table 2.

Selected characteristics of study participants with systemic lupus erythematosus

Characteristic	Value
<u>Sociodemographic</u>	
Mean (SD) age in years	46.2 (11.8)
Age category, <i>n</i> (%)	
18–34	88 (20.2%)
35–49	168 (38.5%)
≥50	180 (41.3%)
Sex, ^a <i>n</i> (%)	
Female	400 (91.7%)
Male	36 (8.3%)
Race, <i>n</i> (%)	
Black	361 (82.8%)
Other	51 (11.7%)
White	24 (5.5%)
Hispanic ethnicity, <i>n</i> (%)	
Hispanic	24 (5.5%)
Not Hispanic	411 (94.5%)
Level of education completed, <i>n</i> (%)	
High school degree or less	102 (23.4%)
Some college/associates degree	164 (37.6%)
College graduate or higher	170 (39.0%)
Currently working, <i>n</i> (%) ^b	
No	221 (52.1%)
Yes	203 (47.9%)
Annual household income, <i>n</i> (%)	
<\$20,000	149 (35.2%)
\$20,000–59,999	168 (74.9%)
≥60,000	106 (25.1%)
Receiving disability benefits, ^c <i>n</i> (%)	
Yes	194 (44.9%)
No	238 (55.1%)
<u>Clinical</u>	
Median (IQR) disease duration, years	14.8 (9.2–22.3)
Median (IQR) SLAQ score	11 (6–16)
Median (IQR) BILD score ^c	2 (1–4)
Cumulative system damage (from BILD ^c), <i>n</i> (%)	
Ocular	134 (30.7%)
Neuropsychiatric	74 (17.0%)
Renal	37 (8.5%)

Characteristic	Value
Pulmonary	66 (15.1%)
Cardiovascular	106 (24.3%)
Peripheral vascular	73 (19.7%)
Gastrointestinal	103 (23.6%)
Musculoskeletal	86 (19.7%)
Dermatologic	36 (8.3%)
Currently taking steroids, <i>n</i> (%)	
Yes	185 (42.5%)
No	250 (57.5%)
Mean (SD) BMI, kg/m ²	30.2 (8.2)
Obesity (BMI ≥30 kg/m ²) <i>n</i> (%)	
Yes	202 (47.5%)
No	223 (52.5%)
Physical activity, ^d <i>n</i> (%)	
Low	317 (73.7%)
Moderate	66 (15.4%)
High	47 (10.9%)
Mean (SD) depression T-score ^e	48.2 (9.2)
Mean (SD) PSS score ^f	15.2 (7.3)

ADL, activity of daily living; BADL, basic ADL; BILD, Brief Index of Lupus Damage (range, 0–46; 46 is maximum damage); BMI, body mass index; GOAL, Georgians Organized Against Lupus (parent study); IADL, instrumental ADL; IQR, interquartile (25th–75th percentile) range; LSA, Life Space Assessment; PSS, Perceived Stress Scale; SLAQ, Systemic Lupus Activity Questionnaire (range, 0–47; 47 is maximum activity); SPPB, Short Physical Performance Battery score (range, 0–12; higher scores = better performance).

Overall *N*=436, except for: ethnicity (*N*=435), income (*N*=423), disease duration (*N*=435), SLAQ score (*N*=417), BMI (*N*=425), physical activity (*N*=430), depressive symptoms score (*N*=418), perceived stress score (*N*=403), medications (*N*=435), SPPB score (*N*=435), fluid cognition (*N*=197; in-person visits only), self-reported physical functioning (*N*=435), and work status (*N*=424).

^aRepresents sex assigned at birth.

^bFrom the Work Productivity and Activity Impairment Questionnaire: General Health v. 2.0.

^cFrom the closest GOAL assessment.

^dFrom the International Physical Activity Questionnaire – Short Form.

^eFrom the Patient Reported Outcomes Measurement Information System (PROMIS) Depression Short Form-8a.

^fFrom Cohen's 10-item PSS (range, 0–40; higher scores representing greater perceived stress).

Table 3.

Any limitations in instrumental and basic activities of daily living among individuals with systemic lupus erythematosus, by selected participant characteristics

Characteristic	Any limitation in:			
	IADLs		BADLs	
	No. (%)	aOR ^a (95% CI)	No. (%)	aOR ^a (95% CI)
Age category				
18–34	40 (45.4%)	1.00 (ref.)	28 (31.8%)	1.00 (ref.)
35–49	98 (58.3%)	1.65 (0.98–2.79)	77 (45.8%)	1.74 (1.01–3.02)
≥50	107 (59.4%)	1.78 (1.06–2.99)	86 (47.8%)	1.94 (1.13–3.34)
<i>p</i> ^b	<0.001		0.04	
Sex				
Female	229 (57.3%)	1.00 (ref.)	180 (45.0%)	1.00 (ref.)
Male	16 (44.4%)	0.60 (0.30–1.21)	11 (30.6%)	0.53 (0.25–1.11)
<i>p</i> ^b	0.1		0.1	
Race				
Black	208 (57.6%)	1.00 (ref.)	169 (46.8%)	1.00 (ref.)
Other	13 (54.2%)	0.92 (0.40–2.12)	6 (25.0%)	0.40 (0.15–1.04)
White	24 (47.1%)	0.63 (0.35–1.14)	16 (31.4%)	0.49 (0.26–0.93)
<i>p</i> ^b	0.4		0.02	
Hispanic ethnicity				
Hispanic	12 (50.0%)	0.94 (0.38–2.33)	7 (29.2%)	0.79 (0.29–2.12)
Not Hispanic	233 (56.7%)	1.00 (ref.)	184 (44.8%)	1.00 (ref.)
<i>p</i> ^b	0.5		0.1	
Level of education				
≤High school	66 (64.7%)	2.20 (1.31–3.71)	50 (49.0%)	2.11 (1.25–3.55)
Some college	101 (61.6%)	1.88 (1.21–2.93)	88 (53.7%)	2.51 (1.59–3.97)
≥College graduate	78 (45.9%)	1.00 (ref.)	53 (31.2%)	1.00 (ref.)
<i>p</i> ^b	0.002		<0.001	
Annual household income				
<\$20,000	99 (66.4%)	3.20 (1.80–5.68)	80 (53.7%)	2.88 (1.60–5.18)
\$20,000–59,999	95 (56.6%)	2.06 (1.19–3.57)	77 (45.8%)	2.09 (1.18–3.70)
≥60,000	43 (40.6%)	1.00 (ref.)	30 (28.3%)	1.00 (ref.)
<i>p</i> ^b	<0.001		<0.001	
Receiving disability benefits				
Yes	141 (72.7%)	3.53 (2.31–5.39)	116 (59.8%)	3.10 (2.05–4.69)
No	102 (42.9%)	1.00 (ref.)	73 (30.7%)	1.00 (ref.)
<i>p</i> ^b	<0.001		<0.001	
SLAQ score				
≥Median	149 (79.3%)	6.49 (4.15–10.2)	130 (69.2%)	7.35 (4.70–11.5)
<Median	85 (37.1%)	1.00 (ref.)	53 (23.1%)	1.00 (ref.)

Characteristic	Any limitation in:			
	IADLs		BADLs	
	No. (%)	aOR ^a (95% CI)	No. (%)	aOR ^a (95% CI)
<i>p b</i>	<0.001		<0.001	
BILD score				
≥Median	107 (65.2%)	1.76 (1.17–2.66)	88 (53.7%)	1.73 (1.16–2.60)
<Median	138 (50.7%)	1.00 (ref.)	103 (37.8%)	1.00 (ref.)
<i>p b</i>	0.003		0.001	
On steroids				
Yes	110 (59.5%)	1.39 (0.93–2.08)	84 (45.4%)	1.24 (0.83–1.86)
No	134 (53.6%)	1.00 (ref.)	106 (42.4%)	1.00 (ref.)
<i>p b</i>	0.2		0.5	
Obesity				
Yes	120 (59.4%)	1.17 (0.78–1.74)	98 (48.5%)	1.22 (0.82–1.83)
No	119 (53.4%)	1.00 (ref.)	88 (39.5%)	1.00 (ref.)
<i>p b</i>	0.2		0.06	
Physical activity				
Low	204 (64.4%)	1.00 (ref.)	161 (50.8%)	1.00 (ref.)
Moderate	27 (11.1%)	0.41 (0.23–0.71)	20 (30.3%)	0.48 (0.27–0.87)
High	13 (5.3%)	0.21 (0.11–0.43)	9 (19.2%)	0.25 (0.12–0.54)
<i>p b</i>	<0.001		<0.001	
Depression T-score				
≥Mean	154 (69.5%)	3.41 (2.26–5.15)	125 (56.1%)	2.98 (1.97–4.51)
<Mean	81 (41.1%)	1.00 (ref.)	61 (31.0%)	1.00 (ref.)
<i>p b</i>	<0.001		<0.001	
PSS score				
≥Mean	141 (69.1%)	2.72 (1.80–4.11)	115 (56.4%)	2.47 (1.64–3.74)
<Mean	90 (45.2%)	1.00 (ref.)	68 (34.2%)	1.00 (ref.)
<i>p b</i>	<0.001		<0.001	

BILD, Brief Index of Lupus Damage; BMI, body mass index; PSS, Perceived Stress Scale; SLAQ, Systemic Lupus Activity Questionnaire. SLAQ median=12 (*n*=188 ≥median/*n*=229 <median); BILD median=3 (*n*=164 ≥median/*n*=272 <median); depression T-score mean=48.2 (*n*=223 ≥mean/*n*=197 <mean); PSS score mean=16 (*n*=204 ≥mean/*n*=199 <mean).

^a Age-, sex-, and race-adjusted odds ratio.

^b By χ^2 or Fisher's exact test, as appropriate.