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An abstract of
a thesis submitted to the Faculty of Emory College of Arts and Sciences
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Abstract

Patient Comprehension of a Multidomain Physical Functioning Report for Systemic Lupus Erythematosus

By Grace Xu

BACKGROUND: Systemic lupus erythematosus (SLE) is a chronic inflammatory disease that may affect men and women of all ages. Lupus patients suffer from a reduced quality of life, including decreased physical functioning. The aim of the current study was to survey SLE patients regarding their comprehension of an individualized, patient-friendly report that provides information across multiple domains of physical functioning. Here, we assessed whether 1) patient-reported comprehension of the report differs by patient characteristics and whether 2) patient-reported comprehension is reflected by concordance between self-evaluated and actual functioning.

METHODS: Individualized reports (including pictorial representations of several domains of physical function: activities of daily living, falls, physical performance, patient-reported physical functioning, and community mobility) were delivered to 59 lupus patients with existing data on these measures. Of these, 47 (79.7%) completed an online survey about their individualized report. Ease of interpretation for each domain was dichotomized as very easy vs. not; differences by characteristics were assessed by Fisher's exact test. Self-evaluated functioning for each domain was dichotomized as very well vs. not; actual functioning was dichotomized for each domain; concordance was assessed by percent agreement and kappa values.

RESULTS: Reported ease of interpretation ranged from 70.2% to 85.1% across the domains of physical function. Ease of interpretation was lower among those who were black, and female and who had lower cognitive scores; there was greater variation by age. No differences were statistically significant. Percent agreement between self-evaluated and actual functioning ranged from 63.8% to 76.6%. With the exception of falls (κ=0.7), kappa values indicated weak to no agreement across each section of the report.

CONCLUSION: In this pilot, a report that provides at-a-glance information on physical functioning for lupus patients was associated with high self-reported comprehension but low concordance between actual and self-evaluated functioning. Targeted, culturally appropriate efforts may be needed to increase equity in comprehension. Future studies can help determine how clinical encounters may be improved with a real-time functioning report.

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Background

Systemic Lupus Erythematosus

Systemic lupus erythematosus (SLE), commonly known as lupus, is a chronic autoimmune disease that predominantly affects young women of childbearing age, although it also affects men and women of all ages. The disease is caused by the production of antibodies that are mistakenly directed against an individual's own tissues and organs, resulting in widespread inflammation.[1] SLE is often called "the disease of a thousand faces" and has a variety of clinical manifestations which may include skin rashes, swollen joints, and debilitating fatigue.[2] The symptoms of SLE will vary for each patient, ranging in severity from mild cutaneous inflammation to multiple organ failure.[3] Afflicted individuals may also experience flares, which are measurable increases in disease activity that involve new clinical symptoms, such as a worsening rash or oral ulcers.[4] The cause of SLE has not yet been identified, but has been linked to a genetic predisposition which may trigger the immune system to produce autoantibodies. [5] Given the complex nature of SLE, treatment options remain limited. Corticosteroids and immunosuppressant drugs are the mainstay of treatment but remain poorly tolerated in a sizeable proportion of patients,[2] with side effects that include weight gain, mood changes, and increased susceptibility to infections.

The true prevalence of SLE remains unknown but is estimated to affect 1.5 million Americans.[6] The incidence of SLE has increased to 16,000 new cases per year, which may be attributed to enhanced diagnostic capabilities and increased awareness of the disease.[6] The typical age of onset is between 15 and 44 years and primarily affects females with a 9:1 gender bias.[2] The disease tends to impact patients during their most productive years of life and substantially increases the risk of work impairment, activity limitation, and permanent disability.[7] Patients who develop the disease after the age of 50 are considered late-onset SLE and have, on average, an lesser degree of disease activity.[8] However, older age at onset has been associated with negative outcomes in terms of both morbidity and mortality. Racial and ethnic disparities in lupus are widely known, with non-white populations experiencing an earlier age of onset and greater disease damage.[9] Black women affected by SLE disproportionately suffer from premature death and have mortality rates that are up to three times greater than white women.[10] Socioeconomic factors such as fewer years of education, area level poverty, and weak social support have also been associated with adverse disease outcomes.[11,12] Among patients with SLE, cardiovascular disease has emerged as the leading cause of death, followed closely by infection and renal failure.[13] While mortality rates remain two to five times higher than those in the general population, in general, life expectancy has increased dramatically for lupus patients, with 10 year survival now estimated at 90%.[14] Furthermore, the older population in the US is rapidly expanding, which has increased the pool of individuals at risk of developing late-onset SLE.[8] Combined, these trends suggest a rapidly aging population of patients with SLE, who are at risk for functional impairment due to both older age and disease. This impairment may limit patients' ability to participate in work and daily activities[2] and to live independently as they age.

The focus of treatment for SLE has begun to shift toward improving Health-Related Quality of Life (HRQOL), in addition to lowering activity and limiting organ damage.[15] Past studies have shown that patients with SLE generally score 25-30% lower than the general population and have significantly worse health status on all subscales of functioning.[16] The greatest effect sizes were observed in the domains of general health and physical functioning, which have been identified as primary needs in SLE.[3] When compared to other chronic conditions, such as congestive heart failure and depression, patients with SLE performed significantly worse across all measures of physical and mental health.[17] Multiple common symptoms in SLE, which include muscle-related disability, cognitive dysfunction, and widespread pain, contribute to poor HRQOL.[18,19] Furthermore, SLE patients of all ages perceive substantial impairment in daily functioning and demonstrate poor physical performance that is comparable to what is seen among older populations (Figure 1).[16] Together these patterns suggest that a multidisciplinary, geriatric approach to SLE care—in addition to traditional, disease-based care—might be beneficial in these patients, regardless of age.

Potential Role of Functional Assessment in SLE

Functional status is considered the “sixth vital sign” and often serves as a stronger predictor of patient outcomes than acute physiological measures.[20,21] However, the majority of medical records lack documentation of functional status and demonstrate poor sensitivity for detecting impairment.[20] The prevalence of impairment was consistently lower in medical records than at interview with patients, which served as the reference standard.[20] Unrecognized functional impairment in SLE may lead to care that is not responsive to patients’ needs and thus, not patient-centered.[22] Patient-centered care is a model of healthcare in which “patient values guide all clinical decisions” and remains a highly desired outcome for SLE patients.[23] Failure to provide patient-centered care may cause poor treatment adherence, adverse HRQOL outcomes, and poor patient-physician interactions. Given the chronic nature of SLE, adherence to treatment is particularly crucial for patients, who may require a lifetime of therapy and polypharmacy for comorbidities.[24] However, evidence suggests that there is significant discordance between SLE patients and providers in their perceptions of disease burden (Figure 1).[22] Patients were likely to assign the highest concern to aspects of HRQOL that were adversely impacted by lupus. The greatest unmet needs of SLE patients were related to physical functioning and the activities of daily living.[25] In contrast, physicians' highest ranked concerns focused on organ disease and damage. Patients were more likely to assess health outcomes based on physical and psychological well-being, which were not assessed by provider-scored disease activity instruments.[22]

The high variability of symptoms in SLE emphasizes the importance of providing care that is responsive to patients' needs (Figure 1).[26] Knowledge of functional status has the potential to identify individuals for whom resources are most needed, improve patient satisfaction with treatment, and determine targets for intervention.[22] Individuals who reported positive patient-physician interactions were more likely to adhere to treatment, disclose health concerns to physicians, and favorably perceive their future health.[22] However, previous studies have largely relied on self-reported information to assess HRQOL. Objective measures of physical functioning, particularly with respect to movement, have not been studied as readily in the setting of SLE.[27] Additionally, measurements of physical functioning across multiple domains that are essential for independent living (such as activities of daily living, history of falls, and community mobility) are generally lacking.[18] The combination of measures, relative to patient-reported functioning alone, provides information needed for a complete understanding of HRQOL to both patients and providers.

Preliminary Studies

INstant Functional Outcomes Report for Meaningful Encounters in Dialysis (INFORMED)

In a previous study, our team developed a comprehensive, patient-friendly report for patients receiving dialysis. The INstant Functional Outcomes Report for Meaningful Encounters in Dialysis (INFORMED) pilot study (1) developed an app to collect data on multiple domains of functioning and create an individualized report and (2) assessed the utility of the delivery of the report in a cohort of 43 predominantly black end stage renal disease patients receiving hemodialysis and their providers (Figure 2).[28] Functioning in this pilot was measured across five domains: physical performance, self-reported physical functioning, falls, activities of daily living, and community mobility (Figure 3). Individualized paper reports containing pictorial representations of each domain of functioning were delivered to participants immediately after measurements were completed. Overall, the report was well-received by patients and providers. One month follow up visits were conducted with patients as they were dialyzing to assess utility of the report. Most patients (55%) reported wanting to discuss the report with their provider in a future appointment, and all reported willingness to undergo future functional assessments.[28] The majority of providers (87.5%) reported that they felt comfortable discussing the report with their patients.[28] More than one third (37.5%) noted that it led to better communication with patients and all providers felt that the information was important for patient care.[28]

Georgians Organized Against Lupus (GOAL) cohort

GOAL is an ongoing, large cohort of predominantly African American patients with SLE from metropolitan Atlanta, Georgia (Figure 2). Participants of GOAL were primarily recruited from the existing Georgia Lupus Registry, a population-based registry funded by the Centers for

Disease Control and Prevention. aimed to estimate the incidence and prevalence of SLE in metropolitan Atlanta.[6] Cases were defined as meeting >4 of the 11 criteria defined by the American College of Rheumatology (ACR).[29] Patients not included in the registry but who were receiving SLE treatment from the lupus clinics at Emory University, Grady Memorial Hospital (a public hospital for low-income patients in Atlanta), or from community rheumatologists were recruited to enrich the cohort. All participants were recruited by mail, by telephone, or in person, with subsequent assessments performed annually since Wave 1 (baseline; September 2011-September 2012). A total of 850 participants who were aged ≥18 years with a documented diagnosis of SLE (≥4 revised American College of Rheumatology (ACR) criteria or 3 ACR criteria with a final diagnosis of SLE by a board-certified rheumatologist) were included in Wave 1.

Approaches to Positive, Patient-Centered Experiences of Aging in Lupus (APPEAL) pilot study

In 2016-2017, our team recruited 60 patients from the GOAL cohort to participate in the Approaches to Positive, Patient-centered Experiences of Aging in Lupus (APPEAL) ancillary pilot study (Figure 2). The aim of this study was to estimate the prevalence of impairment across multiple physical and cognitive functioning domains and whether this prevalence differed according to participant characteristics.[16] Functioning data were obtained from a series of performance tests and questionnaires administered during study visits (October 2016—April 2017). Functioning in this pilot was measured across the same domains as in the INFORMED study described above: physical performance, self-reported physical functioning, falls, activities of daily living, and community mobility (Figure 3). Additionally, cognitive functioning was assessed to better understand functional impairment in patients with SLE. In this cohort, impairment was common across multiple domains of physical functioning and similar to that seen in geriatric populations. The mean overall physical performance score (from the SPPB) was 8.8 (maximum=12), only slightly higher than the average score of 8.2 for the 71+year-olds in whom the SPPB was developed. The overall self-reported physical functioning score was 38.8, well below the norm of 50. Participants were more likely to report difficulties with the independent activities of living than the basic activities of daily living. Nearly half (45%) of the participants reported falling in the past year. Only 65.0% reported the ability to get around their neighborhoods without assistance. Mean adjusted T scores for functioning were below average for overall fluid cognition (41.4 [19th percentile]).

Current Study

The aim of the current study was to survey SLE patients regarding their comprehension of an individualized, patient-friendly report that provides information across multiple domains of physical functioning (Figure 1). To address this aim, we leveraged our prior studies (Figure 2). First, the report developed in the INFORMED pilot study was minimally modified to accommodate a different measure of self-reported functioning and for patients with SLE, who are similar demographically to those with end-stage renal disease. Then, the existing data collected from the APPEAL pilot study were then used to generate individualized physical functioning reports (including pictorial representations of several domains of physical function: activities of daily living, falls, physical performance, patient-reported physical functioning, and community mobility) and delivered to the remaining members of the APPEAL cohort, along with a survey regarding the utility, acceptability, and comprehension of their individualized report (Appendix).

In this study, we focus on the comprehension of the report, as the potential use of the report in future research and in the clinic depends on patients being able to understand their results without training. Specifically, it is important to know whether patient-reported comprehension of the report differs by patient characteristics (age, race, sex, cognitive functioning), in order to tailor interventions as needed. Further, it is important to know whether patient-reported comprehension is reflected by concordance between self-evaluated functioning in response to their report and their actual performance, based on the underlying data.

Study Aims

Aim 1: Compare self-reported ease of interpretation by patient characteristics (age, race, sex, cognitive functioning)

Aim 2: Assess concordance between self-evaluated functioning and actual functioning

Hypotheses

1. Older, black, female, and lower cognitive functioning patients will report greater difficulty with ease of interpretation
2. Patients who report lower self-evaluated functioning in response to their report will demonstrate lower actual functioning in the assessments

Methods

Study Design and Population

Individualized physical functioning reports were delivered to 59 remaining participants in the APPEAL pilot study (n=1 deceased) in early 2019 (Figure 2). Of these, 47 (79.7%) completed an online REDCap survey about the utility, acceptability, and comprehension of their individualized report (Appendix). The Emory University Institutional Review Board approved the study protocol and all participants provided informed consent prior to completing the survey.

Aim 1: Compare self-reported ease of interpretation by patient characteristics (age, race, sex, cognitive functioning)

Study Variables

Ease of Interpretation

Participants were asked "How easy was it understand your results on (section of report)?" (Appendix). Ease of interpretation was assessed on a Likert scale, scored 1-5, with higher scores representing greater difficulty with interpretation. The responses were heavily skewed towards participants evaluating the report as "very easy" to interpret (Figure 4). For analyses, participants were dichotomized as having a very easy interpretation vs. all other ratings.

Patient Characteristics

Ease of interpretation was assessed by age, dichotomized at the mean age of 50 years (older ≥50 vs. younger <50); race (black vs. other, given that the participants were predominantly black); sex (male vs. female); and cognitive functioning (low = scoring >1 SD below the mean, high = otherwise). All data were self-reported except for cognitive functioning, which is defined as the "ability to shift thoughts and adapt behavior to new conditions."

Cognitive functioning was assessed via the NIH Toolbox fluid cognition battery. [30] The NIH Toolbox is a computerized exam used to assess mental processes involved in gaining knowledge and comprehension.[30] Raw scores were converted to T scores adjusted for age, sex, race, and education, such that scores of 50 represented the mean for persons of the same sex, race, and educational attainment with a standard deviation (SD) of 10 points. For example, a person with a T score of 40 is 1 standard deviation below the mean.

Statistical Analysis

Scores for physical and cognitive performance and patient-reported utility of the report were reported as means and percentages. Comparisons of scores across characteristics were tested by 2-sample t test (continuous variables) and Fisher's exact test (categorical variables). All analyses were performed using Stata, version 15.0, and the threshold for statistical significance was set at $\alpha = 0.05$.

Aim 2: Assess concordance between self-evaluated and actual functioning

Study Variables

Self-Evaluation of Performance

Participants were asked "How well do you think you were doing in terms of (section of report)?" (Appendix). Self-evaluation of performance was assessed on a Likert scale, scored 1-4, with higher scores representing poor self-evaluated functioning. The responses were moderately skewed towards participants evaluating themselves as functioning "very well"

(Figure 5). For analyses, responses were dichotomized as performing very well vs. all other ratings.

Activities of daily living (ADLs)

The term “activities of daily living” refers to the common, everyday tasks needed for independent living.[31] The basic activities of daily living (BADLs) are defined as the fundamental skills needed to manage basic physical needs (walking, dressing, bathing, toileting, transferring from the bed to a chair, grooming, and eating).[31] The instrumental activities of daily living (IADLs) are defined as the more complex activities that are related to independent living in a community (using telephone, shopping, food preparation, housework, laundry. transportation, managing finances, managing medications).[32] Basic and instrumental ADLs were assessed by the Katz Index of Independent Living and the Lawton Instrumental Activities of Daily Living scale, respectively and scored yes/no for independence in each of the functions.[33,34] Functioning very well was defined as having complete independence on all basic ADLs and instrumental ADLs (e.g., shopping independently for all needs or for only small purchases); not very well was defined as requiring assistance on at least one (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 experienced and whether they had sought medical attention for any of their falls during the past year. Fear of falling during daily tasks was assessed via the Falls Efficacy Scale (FES), which measures confidence in performing a range of activities of daily living without falling on a ten point scale (10 = no confidence, 1 = confidence).[35] The FES is scored 0–100, with higher scores representing greater fear of falling, and a score of 70 or above indicates that an individual has a fear of falling.[35] Functioning very well was defined as reporting no falls in the past 12 months and also having no fear of falls during daily activities; not very well was defined as falling at least once or scoring at or above 70 on the Falls Efficacy Scale.

Physical functioning

Patient-reported physical functioning was measured via the Patient-Reported Outcomes Measurement Information System (PROMIS) Physical Functioning-Short Form 12a. Scores were based on self-reported capability in physical functioning and the activities of daily living.[36] 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. Functioning very well was defined as having a T score ≥ 50 (average or above) on the PROMIS assessment of physical functioning; not very well was defined as having a T score <50 (below average).[36]

Physical performance

Physical performance was assessed via the Short Physical Performance Battery (SPPB), which has been used extensively in older adults to assess physical and functional health.[37] The SPPB was comprised of 3 tests of objective lower body function: balance (ability to hold standing poses in different foot positions), gait speed (fastest of two 4-meter walks at the regular pace), and lower body strength (speed in completing 5 chair stands without using the arms).[38] All individual tests were scored 0–4 (with higher scores indicating higher levels of physical performance, such that a score of 0 indicated “unable to perform”). The overall score was the sum of the 3 individual scores (range, 0–12). Performing very well defined as having a maximum score of = 12; not very well was defined as having a score < 12 since this score represents being in the upper quartile for individuals over the age of 70.[38]

Life Space

Life space and community mobility may be visualized as a pattern of areas defined by the distance extending from one's bedroom to movement beyond one's town. The University of Alabama at Birmingham (UAB) Study of Aging Life Space Assessment (LSA) is widely used among community-dwelling older adults to assess reductions over time in the frequency or independence of travel.[39] The LSA captures community mobility 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 (range, 0-120).[39] Functioning very well was defined as making it out of town weekly without help in last month; not very well was defined as not making it out of town weekly or needing assistance to do so.

Statistical Analysis

Kappa values (κ) and percent agreement between self-evaluated and actual functioning were calculated to assess concordance. A kappa value is a quantitative measure of the magnitude of agreement between two observations for categorical items.[40] A kappa value accounts for agreement due to chance (50%) and thus serves as a more robust measure than simple percent agreement.[40] Kappa values range from -1 to +1, such that 1 indicates perfect agreement, 0 indicates agreement equivalent to chance, and negative values indicate agreement less than chance.[41]

Overall Review of Report

Participants were asked whether they recalled answering questions during the pilot study about each section of the report; whether they perceived it would be useful for their treatment or other personal care planning to discuss each section of the report with anyone; to identify which parts of the report were difficult to understand; whether they believed that it would be useful for their treatment or other personal care planning to discuss this part of the report with anyone; why they would like to discuss each section of the report; and whether they would be interested in receiving a similar report in real time; whether they would be willing to arrive early to appointments to complete the necessary tests and surveys; and how often they would be willing to undergo future functioning assessment (Appendix).

Results

Characteristics of study cohort

Table 1 shows that overall mean age of participants included in our study was 49.6 years, 8.5% of the participants were male, and 78.7% were black. Participants reported difficulty in performing an average of 5.3 activities of daily living (maximum = 13). Nearly half (44.7%) of the participants reported falling at least once in the past year and 10.6% had a fear of falling. The mean overall physical performance score (from the Short Physical Performance Battery) was 8.9 (maximum = 12). Impairment was also common in self-reported functional domains. The mean life space assessment score (range, 0-120, higher scores=greater community mobility) was 52.5. The mean T scores for patient-reported physical functioning and overall fluid cognition were both 1 standard deviation below the mean value.

Aim 1: Compare self-reported ease of interpretation by patient characteristics (age, race, sex, cognitive functioning)

Table 2 shows that there were no statistically significant differences in ease of interpretation by patient characteristic. Across all five domains, black vs. other participants, as well as lower cognitive functioning vs. higher cognitive functioning participants, had greater difficulty in ease of interpretation. There were also differences in ease of interpretation by sex, such that male participants were more likely to indicate that the report was “very easy” to interpret across all five domains. By age, there was greater variation in ease of interpretation across each section of the report, with older (≥50) vs. younger (<50) participants reporting greater and less ease with interpreting different domains (Table 3). Few participants indicated that the report as “somewhat difficult” or “very difficult” to interpret (range, 0-2.1%).

Activities of Daily Living

Overall, 70.2% of participants indicated that the activities of daily living section of the report was “very easy” to interpret and 23.4% indicated that it was “somewhat easy” to interpret (Figure 5). By age, older (≥50) vs. younger (<50) patients had higher ease of interpretation for this section (72.0% vs. 68.2%). By race, 90.0% of non-black participants indicated that this section was “very easy” to interpret compared to 64.9% of black participants. By sex, 100% of male participants indicated that this section was “very easy” to interpret compared to 67.4% of female participants. By cognitive functioning, 77.8% of higher functioning participants indicated that the report was “very easy” to interpret compared to 60.0% of lower functioning participants.

Falls

Overall, 85.1% of participants indicated that the falls section of the report was “very easy” to interpret. By age, older (≥50) vs. younger (<50) patients had higher ease of interpretation (88.0% vs. 81.8%). By race, 90.0% of non-black participants indicated that this section was “very easy” to interpret compared to 83.3% of black participants. By sex, 100% of male participants indicated that this section was “very easy” to interpret compared to 83.7% of female participants. By cognitive functioning, 92.6% of higher functioning participants indicated that the report was “very easy” to interpret compared to 75.0% of lower functioning participants.

Patient-reported physical functioning

Overall, 74.5% of participants indicated that the patient-reported physical functioning section of the report was “very easy” to interpret and 17.0% indicated that this section was “somewhat easy” to interpret. By age, older (≥50) vs. younger (<50) patients had higher ease of interpretation (77.3% vs. 72.0%). By race, 80.0% of non-black participants indicated that this section was “very easy” to interpret compared to 73.0% of black participants. By sex, 75.0% of male participants indicated that this section was “very easy” to interpret compared to 74.4% of female participants. By cognitive functioning, 81.5% of higher functioning participants indicated that the report was “very easy” to interpret compared to 65.0% of lower functioning participants.

Short Physical Performance Battery

Overall, 74.5% of participants indicated that the Short Physical Performance Battery section of the report was “very easy” to interpret and 14.9% indicated that this section was “somewhat easy” to interpret. By age, older (≥50) vs. younger (<50) patients had higher ease of interpretation (68.0% vs. 81.8%). By race, 90.0% of non-black participants indicated that this section was “very easy” to interpret compared to 70.3% of black participants. By sex, 100% of male participants indicated that this section was “very easy” to interpret compared to 72.1% of female participants. By cognitive functioning, 81.5% of high functioning participants indicated that the report was “very easy” to interpret compared to 65.0% of low functioning participants.

Life Space Assessment

Overall, 76.6% of participants indicated that the Life Space Assessment section of the report was “very easy” to interpret and 12.8% indicated that this section was “somewhat easy” to interpret. By age, older (≥50) vs. younger (<50) patients had higher ease of interpretation (77.3% vs. 76.0%). By race, 80.0% of non-black participants indicated that this section was “very easy” to interpret compared to 75.7% of black participants. By sex, 74.4% of male participants indicated that this section was “very easy” to interpret compared to 72.1% of female participants. By cognitive functioning, 81.5% of high functioning participants indicated that the report was "very easy" to interpret compared to 70.0% of low functioning participants.

Aim 2: Assess concordance between self-evaluated and actual functioning

Figure 5 shows that across all five domains, responses were moderately skewed towards participants evaluating themselves as functioning "very well." Few participants evaluated themselves as performing "poorly" (range, 2.1-12.8%). With the exception of self-reported physical functioning, percent agreement between self-evaluated and actual functioning was high (range, 50.0-79.2%) and kappa values were weak to moderate (range, 0.3-0.7) across all sections of the report.

Activities of Daily Living

Overall, 34.0% of participants evaluated themselves as functioning "very well," 29.8% evaluated themselves as performing "well," and 34.0% evaluated themselves as performing "fairly." Table 3 shows that participants who had performed very well were more likely to rate themselves as doing so compared to those who had not performed very well (57.9% vs 17.9%). The kappa value (0.4) suggests fair agreement between self-evaluated and actual functioning.

Falls

Overall, 46.8% of participants evaluated themselves as functioning "very well," 27.7% evaluated themselves as performing "well," and 23.4% evaluated themselves as performing "fairly." Table 3 shows that participants who had performed very well were more likely to rate themselves as doing so compared to those who had not performed very well (79.2% vs 13.0%). The kappa value (0.7) suggests moderate agreement between self-evaluated and actual functioning.

Patient-reported physical functioning

Overall, 14.9% of participants evaluated themselves as functioning “very well,” 31.9% evaluated themselves as functioning “well,” and 40.4% evaluated themselves as functioning “fairly.” Interestingly, Table 3 shows that participants who had functioned very well were less likely to rate themselves as doing so compared to those who had not functioned very well (0% vs 17.0%). The kappa value (-0.2) suggests percent agreement was less than expected by chance.

Short Physical Performance Battery

Overall, 29.8% of participants evaluated themselves as performing “very well,” 34.0% evaluated themselves as performing “well,” and 29.8% evaluated themselves as performing “fairly.” Table 3 shows that participants who had performed very well were more likely to rate themselves as doing so compared to those who had not performed very well (71.4% vs 22.5%). The kappa value (0.3) suggests weak agreement between self-evaluated and actual functioning.

Life Space Assessment

Overall, 31.9% of participants evaluated themselves as functioning “very well,” 27.7% evaluated themselves as functioning “well,” and 31.9% evaluated themselves as functioning “fairly.” Table 3 shows that participants who had functioned very well were more likely to rate themselves as doing so compared to those who had not functioned very well (50.0% vs 20.7%). The kappa value (0.3) suggests weak agreement between self-evaluated and actual functioning.

Summary of other feedback on report by domain of functioning

The majority of patients (range, 82.3-91.5%) reported that they were able to recall answering questions or performing tests related to their functioning. Most patients (range, 63.8-74.5%) indicated that they perceived the sections of the report to be useful for improving their personal care planning or treatment. Nearly all patients (range, 93.2-100%) reported that they felt comfortable discussing the domains of the report with a healthcare provider. Patients indicated that they were most interested in discussing the report with their rheumatologist (range, 61.7-72.3%) and primary care provider (range, 40.4-55.3%). With regard to purpose in discussion of the report, patients indicated that they were interested in improving communication with their providers (range, 48.9-63.8%); improving their functioning (range, 31.9-63.8%); obtaining needed referrals and services (range, 19.2-27.7%); and setting treatment goals (range, 29.8-42.0%). Overall coherence of the report (range, 87.2-100%) was high. Participants had the greatest difficulty with interpreting the scales and the least difficulty with interpreting the colors.

Overall review of report

Table 5 shows that patients generally reacted positively to the overall report. Most patients indicated interest in receiving a real-time report (87.2%) and a willingness to arrive early to appointments to complete the necessary tests and surveys (89.1%). Nearly all patients (97.9%) reported willingness to undergo future functioning assessment, at frequencies ranging from monthly/every 3 months to annually.

Discussion

In this pilot study of a cohort of patients with SLE, we assessed patient comprehension of a novel, multi-domain physical functioning report developed for lupus. Although no differences were statistically significant, we found that, on average, black, female, and lower cognitive functioning patients had greater difficulty interpreting the report (Table 2). Depending on domain, ease of interpretation varied between older (≥50 years) and younger (<50 years) patients. Table 3 shows that, with the exception of the self-reported physical functioning section of the report, where there was no agreement beyond chance, percent agreement (range, 50.0-79.2%) and kappa values (range, 0.3-0.7) between actual and self-evaluated performance were weak to moderate. Overall, these results suggest that self-reported patient comprehension of the report was high but that understanding of individual levels of functioning was low.

Ease of interpretation ranged from 70.2% to 85.1% by domain of physical functioning. Participants had the greatest difficulty with interpreting their results for the activities of daily living and the least difficulty with interpreting their results for the falls section of the report. Black, female, and lower cognitive functioning participants were less likely to report that each domain was “very easy” to interpret. Differences in ease of interpretation may be related to differences in health literacy. For example, health literacy is, on average, lower among black vs. other patients.[42] In general, lower cognitive functioning patients, who had more difficulty with interpretation in our study, also have greater difficulty interpreting and acting upon medical information.[43] Compared to younger patients, older patients had greater ease of interpretation for the falls (88.0% vs 81.0%) and activities of daily living (72.0% vs 68.2%) sections of the report, which may be attributed to their greater familiarity with these assessments of functioning or their experiences with limitations in these areas.[32] These results suggest that patient-reported interventions may be tailored as needed for populations of SLE patients who may have greater difficulty with interpreting their individualized results. However, it should be noted that we were somewhat limited in our ability to compare ease of interpretation by characteristics in this small cohort, particularly by sex and race.

We also found that concordance between self-evaluated and actual physical functioning was low. Responses were moderately skewed towards participants evaluating themselves as performing “very well” and “well” (Figure 4). Participants who had functioned “very well” were more likely to evaluate themselves as doing so. Table 3 shows that the highest percent agreement (79.2%) and kappa value (0.7; moderate agreement) were observed in the falls section of the report. In contrast, the patient-reported physical functioning section of the report had the lowest (0%) percent agreement and a negative kappa value, which suggest that participants were unlikely to evaluate themselves as functioning “very well.” Interestingly, participants were most likely to function “very well” on the falls section of the report (58.5%) and also reported that this section was the easiest to interpret (85.1%). These data suggest that there may be a correlation between participants’ actual performance and their ability to comprehend the information presented to them in the report.

Other feedback on the report show that patients generally reacted positively to its future use. Most indicated interest in receiving a real-time report as well as a willingness to arrive early to appointments and undergo additional functional assessment. Nearly all patients reported that they felt comfortable discussing the domains of the report with a healthcare provider. Participants were most likely to want to discuss sections of the report with their rheumatologist (range, 61.7-72.3%), with whom they interact most closely to treat chronic inflammation. These results suggest that the report may be further tailored for SLE to facilitate discussions with multiple providers.

The combination of objective performance, as assessed by the Short Physical Performance Battery, and patient-reported outcomes (PROs) in a single report provides information in a standardized manner that may help to improve specific areas of functioning. PROs are tools that measure patient impression of disease burden and provide valuable information that is not included in physician-based assessments.[44] In this study, PROs were assessed by four domains: activities of daily living, history of falling, patient-reported physical functioning, and life space assessment. Some PROs, such as difficulty transferring without assistance, may result from manifestations of active disease.[19] Multiple studies have validated the use of PROs in patients with SLE as predictors of mortality, and these measures are becoming increasingly important in the shift from disease-centered care for SLE patients.[43]

Our study has several limitations that are worth mentioning. First, generalizability to populations of SLE patients that have a different race/ethnicity or socioeconomic distribution from our metropolitan Atlanta population may be limited. Second, the majority (range, 82.3-91.7%) of patients recalled answering questions about their physical functioning in each domain. However, an inability to recall doing so may have caused patients to report inaccurate self-evaluated functioning or a lower ease of interpretation in response to the report.[45] Third, the small sample size contributes to a lack of power and an inability to adjust for potential confounding factors. Because our method of dichotomizing self-evaluated performance ("very well" vs. all other responses) and ease of interpretation ("very easy" vs. all other responses) is not validated across studies of HRQOL, it is unknown whether the estimated differences reflect clinically important differences in comprehension and performance. Furthermore, the cognitive measures (NIH Toolbox) used are not diagnostic. Thus, using these assessments to identify cognitive impairment requiring clinical intervention is not possible.[30] Lastly, measurements of self-evaluated functioning both before and after delivery of the report may have captured concordance more robustly.

Despite its limitations, our study also has several strengths. Most prior studies of SLE patients have included predominantly white cohorts, despite non-white populations having a greater risk of adverse health outcomes.[46] This study assessed a population-based sample of patients with SLE with adequate representation of black patients.[47] Kappa values showing the concordance between self-evaluated and actual functioning accounted for agreement by chance and validated the percent agreements that were observed in each domain of the report. To our knowledge, this is the first cohort study of SLE patients, to date, that examines patient perceptions of an individualized functioning report.

In conclusion, a report that provides information across multiple domains of physical functioning for SLE patients was associated with high self-reported comprehension. Results of this study will inform the use of the report in future studies, including longitudinal assessments of functioning and the effect of report delivery on subsequent outcomes, such as treatment adherence and PROs. Such studies will help establish patient-centered care strategies for an aging SLE population.[16]

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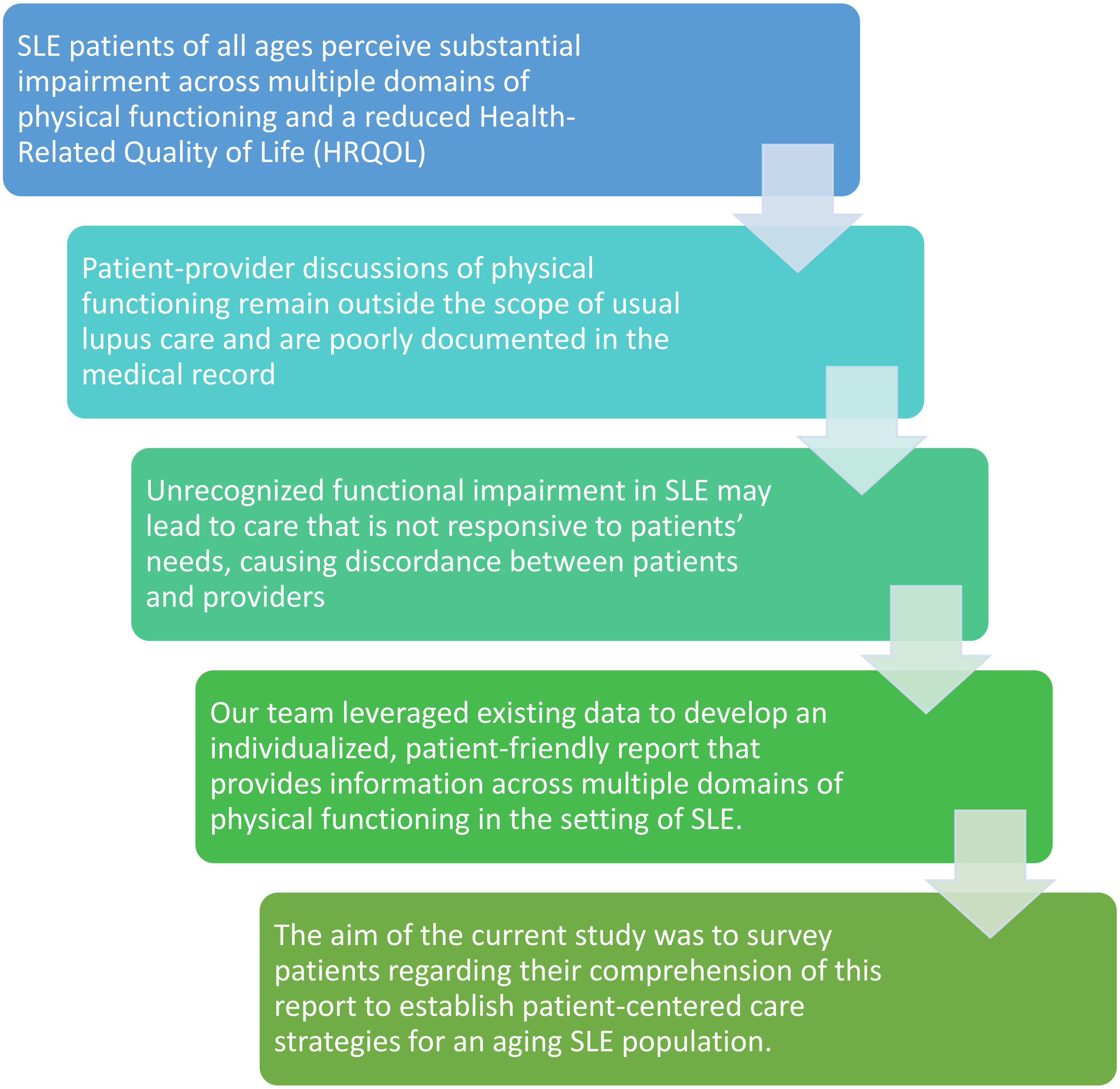
Figures and Tables

Figure 1. Study Rationale.



SLE patients of all ages perceive substantial impairment across multiple domains of physical functioning and a reduced Health-Related Quality of Life (HRQOL)

Patient-provider discussions of physical functioning remain outside the scope of usual lupus care and are poorly documented in the medical record

Unrecognized functional impairment in SLE may lead to care that is not responsive to patients' needs, causing discordance between patients and providers

Our team leveraged existing data to develop an individualized, patient-friendly report that provides information across multiple domains of physical functioning in the setting of SLE.

The aim of the current study was to survey patients regarding their comprehension of this report to establish patient-centered care strategies for an aging SLE population.

Figure 2: Preliminary and current studies.

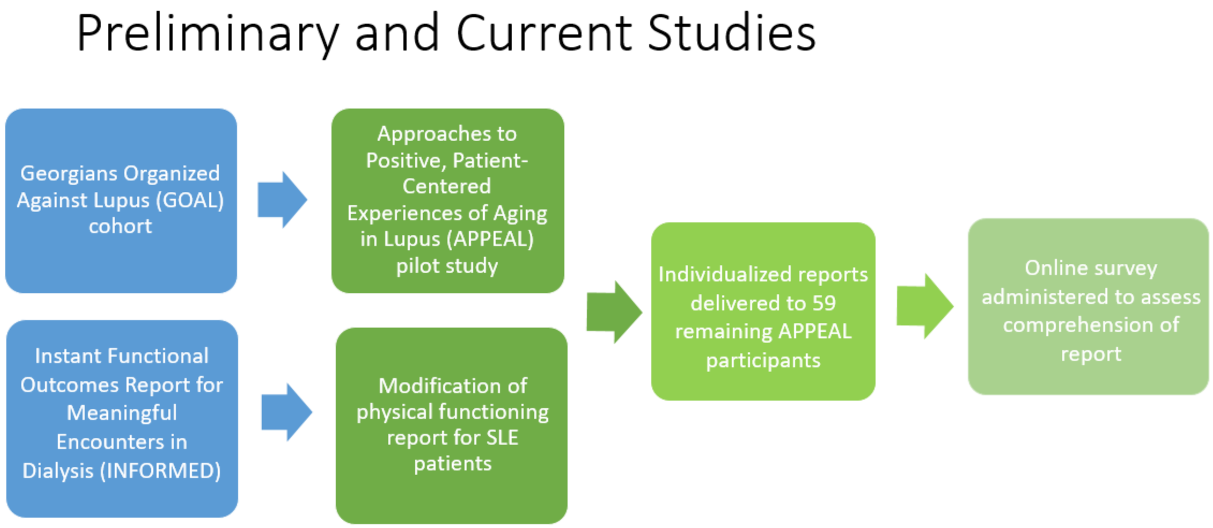
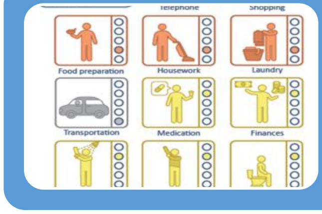


Figure 3: Summary of physical functioning domains.



Activities of Daily Living

- Ability to perform basic and instrumental activities of daily living, assessed by the Katz Index of Independent Living and the Lawton Instrumental Activities of Daily Living scale, respectively (scored yes/no for independence in each of the functions)
- Very well = complete independence on all ADLs
- Not very well = requiring assistance on at least one ADL

Do You Fall?

Falls this year: 2 Needed medical help: 2

Patient-Reported Fall Factors

Not measured

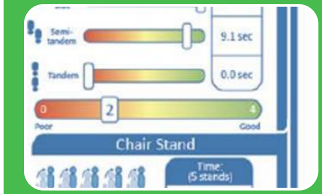
Reported fear of falling: Yes

Falls

- History of falls and fear of falling during daily tasks, assessed by the Falls Efficacy Scale (scale 0-100, higher scores = greater fear of falling)
- Very well = no falls in the past 12 months and scoring <70 on FES
- Not very well = falling at least once and scoring >70 on FES

Patient-reported physical functioning

- Assessed by the Patient Reported Outcomes Measurement Information System (PROMIS) Physical Functioning Short Form 12a (raw scores scaled to T scores)
- Very well = T score >=50 (average or above)
- Not very well = T score < 50 (below average)



Short Physical Performance Battery

- Objective tests of lower body function: balance, gait speed, chair stands (range, 0-12)
- Very well = maximum score = 12
- Not very well = score < 12

Life Space Assessment

- Ability to move or travel to a designated space extending from one's bedroom
- Very well = making it out of town weekly without help in the past month
- Not very well = not making it out of town weekly or requiring assistance to do so

Characteristics of SLE cohort

Table 1. Characteristics of SLE Patients Participating in APPEAL Survey.

Characteristic	**Overall**
N	47
Age, mean (SD)	49.6 (12.3)
Sex	
Male	4 (8.5%)
Female	43 (91.5%)
Race	
Black	37 (78.7%)
Other	10 (21.3%)
Difficulty in Activities of Daily Living[a], mean (SD)	5.3 (1.1)
Fear of falling[b], n (%)	5 (10.6%)
At least 1 fall in the past year[c], n (%)	26 (44.7%)
Patient-reported physical functioning[d] score, mean (SD)	40.3 (9.4)
Short Physical Performance Battery[e] score, mean (SD)	8.9 (2.45)
Life Space Assessment[f] score, mean (SD)	52.5 (35.0)
Overall fluid cognition[g] score, mean (SD)	40.9 (12.5)

[a] Activities of daily living (ADLs) include the basic activities of daily living (*e.g*., bathing, dressing, transferring) and instrumental activities of daily living (*e.g.*, shopping, managing finances); scores dichotomized as any vs. no difficulty performing the activity independently or with minimal help; scores represent the mean number of ADLS in which participants had difficulty.

[b] Fear of falling assessed via the Falls Efficacy Scale (FES), which measures confidence in performing a range of activities of daily living without falling on a ten point scale (10 = no confidence, 1 = confidence); scored 0–100, higher scores = greater fear of falling; a score of 70 or above indicates that an individual has a fear of falling; data represent the number of individuals who had a fear of falling.

[c] Number of falls reported in the past year, data represent the number of individuals who reported at least one fall in the past year.

[d] Patient-reported physical functioning assessed via the PROMIS Physical Functioning Short Form 12a; raw scores were scaled to T scores, such that 50 represented the average score for a general adult population; differences of 10 represented 1 SD, higher scores = better self-reported physical functioning.

[e] Short Physical Performance Battery includes assessments of balance, lower body strength, and gait speed; higher scores = higher levels of physical performance; overall score = sum of scores, scale 0-12.

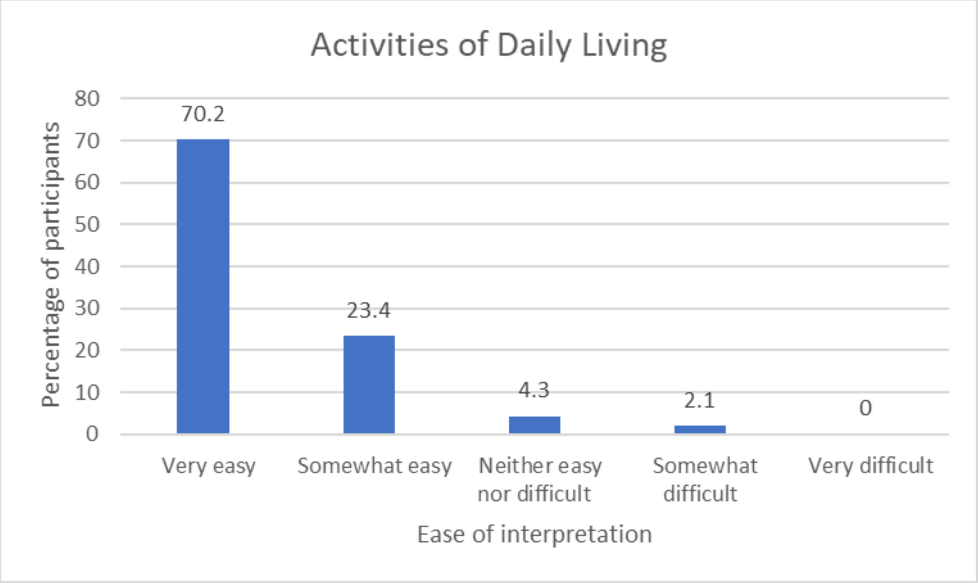
[f] The UAB Study of Aging Life Space Assessment captures community mobility and social participation; scale 0-120, higher scores = greater life-space mobility.

[g] Overall fluid cognition score measures the capacity to reason and solve novel problems; raw scores were scaled to T scores adjusted for age, race, sex, and educational attainment, such that 50 represented the average score; differences of 10 represented 1 SD, higher scores = better functioning.

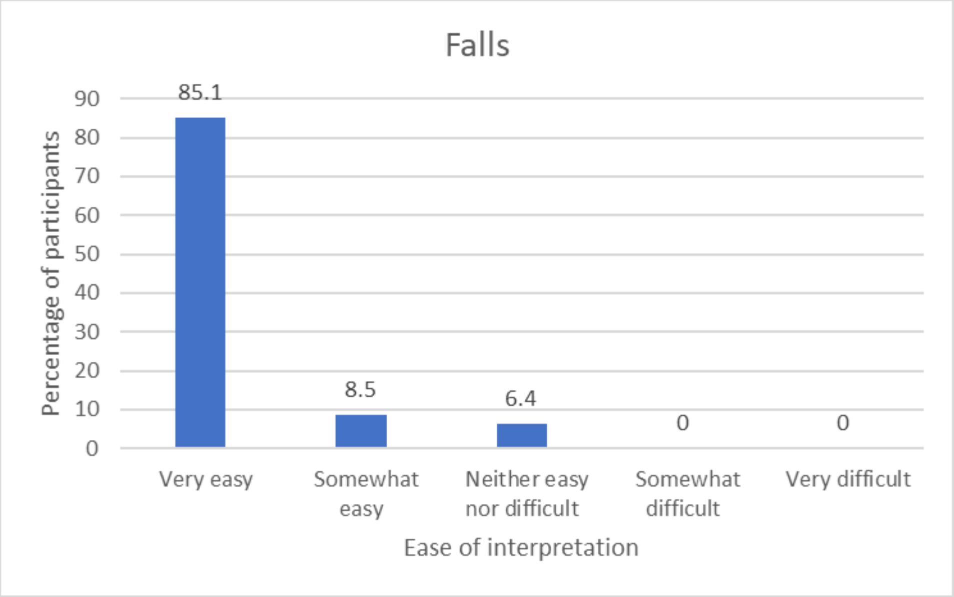
Aim 1: Compare self-reported ease of interpretation by patient characteristics (age, race, sex, cognitive functioning)

Figure 4: Ease of interpretation, by domain of functioning.

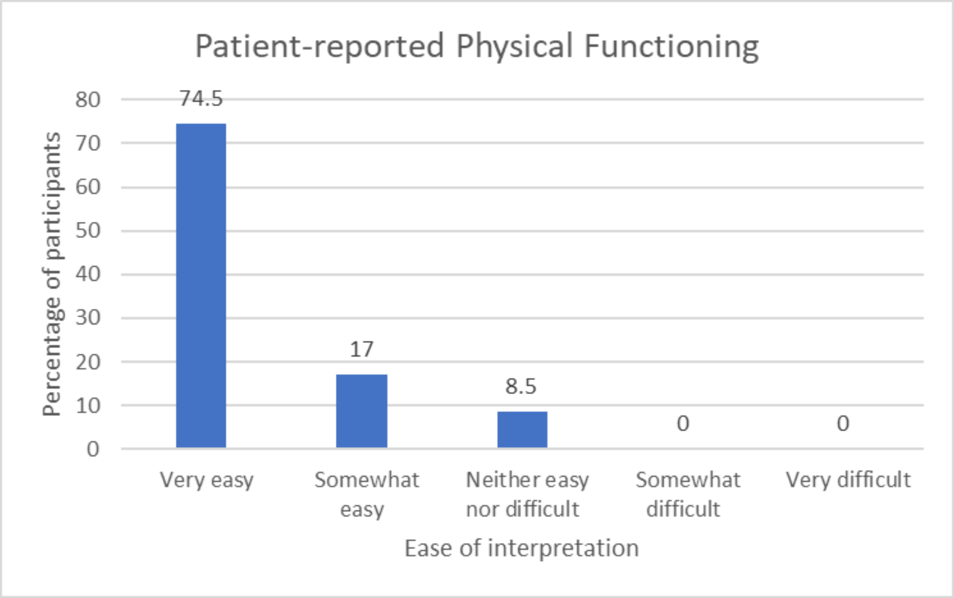
Based on survey responses from 47 patients with systemic lupus erythematosus; assessed on a Likert scale, scored 1-5, with higher scores representing greater difficulty.



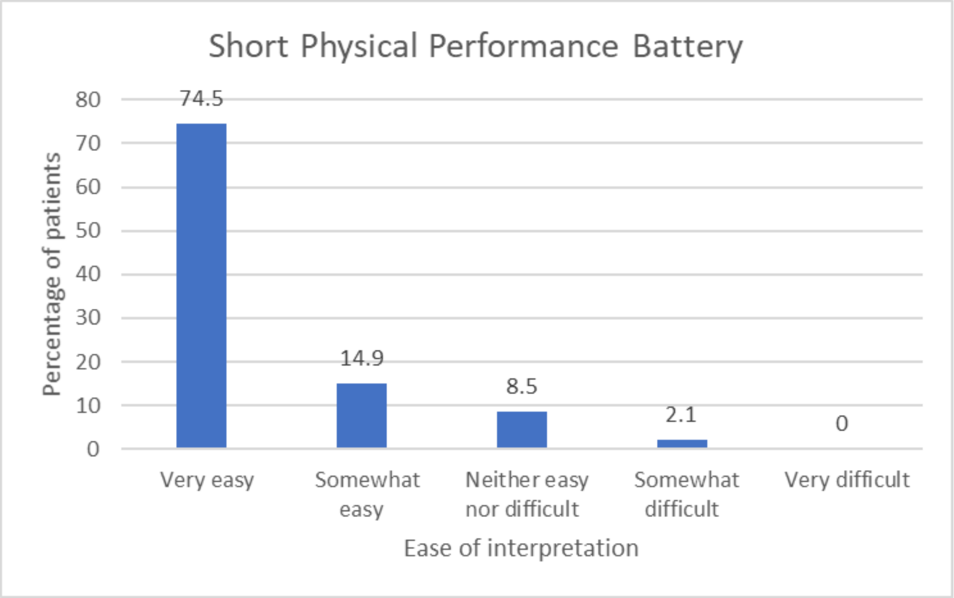
Part A. Ease of interpretation for the activities of daily living.



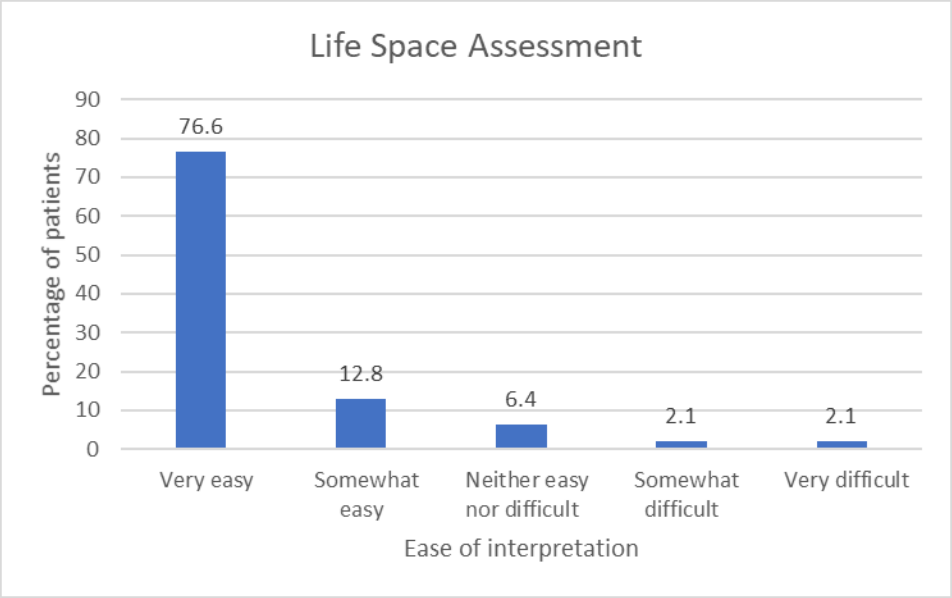
Part B. Ease of interpretation for falls.



Part C. Ease of interpretation for patient-reported physical functioning.



Part D. Ease of interpretation for the Short Physical Performance Battery.



Part E. Ease of interpretation for the Life Space Assessment.

Table 2: Self-reported ease of interpretation across report domains, overall and by patient characteristic.

	Activities of Daily Living	Falls	Patient-reported physical functioning	Short Physical Performance Battery	Life Space Assessment
Overall	70.2%	85.1%	74.5%	74.5%	76.6%
By age					
<50	68.2%	81.8%	77.3%	81.8%	77.3%
≥50	72.0%	88.0%	72.0%	68.0%	76.0%
p[a]	1.0	0.7	0.7	0.3	1.0
By race					
Black	64.9%	83.8%	73.0%	70.3%	75.7%
Other	90.0%	90.0%	80.0%	90.0%	80.0%
p	0.2	0.5	1.0	0.4	1.0
By sex					
Female	67.4%	83.7%	74.4%	72.1%	74.4%
Male	100%	100%	75.0%	100%	100%
p	0.3	0.5	1.0	0.6	0.6
Cognitive Functioning[b]					
Lower	60.0%	75.0%	65.0%	65.0%	70.0%
Higher	77.8%	92.6%	81.5%	81.5%	81.5%
P	0.2	0.1	0.3	0.3	0.5

[a] By paired t-test or Fisher's exact, as appropriate

[b] Cognitive functioning was assessed via the NIH Toolbox fluid cognition battery[30]; raw scores were converted to T scores adjusted for age, sex, race, and education, such that scores of 50 represented the mean for persons of the same sex, race, and educational attainment with a standard deviation (SD) of 10 points; lower cognitive functioning is defined as scoring >1 SD below the mean

Aim 2: Assess concordance between self-evaluated and actual functioning

Table 3: Percentage of patients who rated themselves doing “very well”, overall and by assessed functioning.

	Percent agreement	Among patients not doing “very well” in actual functioning	Among patients doing “very well” in actual functioning	Kappa value
Activities of Daily Living[a]	72.3%	5/28 (17.9%)	11/19 (57.9%)	0.4
Falls[b]	83.0%	3/23 (13.0%)	19/24 (79.2%)	0.7
Patient-reported physical functioning[c]	63.8%	7/41 (17.0%)	0/6 (0%)	-0.2
Short Physical Performance Battery[d]	76.6%	9/40 (22.5%)	5/7 (71.4%)	0.3
Life Space Assessment[e]	68.1%	6/29 (20.7%)	9/18 (50.0%)	0.3

[a] Activities of Daily Living: very well = completely independent on all ADLs and IADLs, not = dependent on at least one

[b] Falls: very well = no falls and no fear of falls, not = at least 1 fall or fear of falling (FES>70)

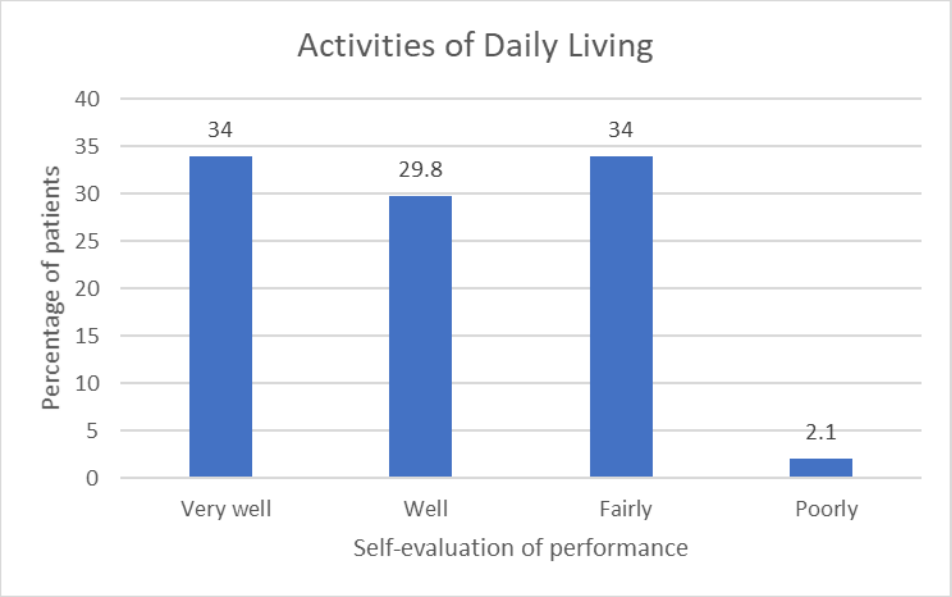
[c] Physical Functioning: very well = scaled score ≥ 50, not = scaled score <50

[d] Short Physical Performance Battery: very well = scaled score ≥ 12, not = score < 12 since this represents being in the upper quartile for all three domains

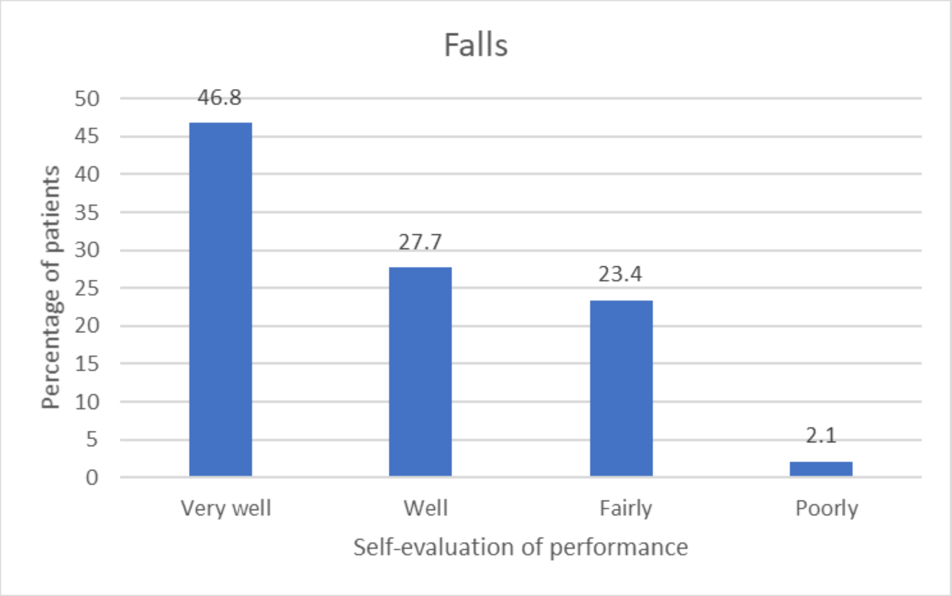
[e] Life Space Assessment: very well = made it out of town weekly without help in last month; not = did not make it out of town weekly or needed assistance

Figure 5: Self-evaluation of performance, by domain of functioning

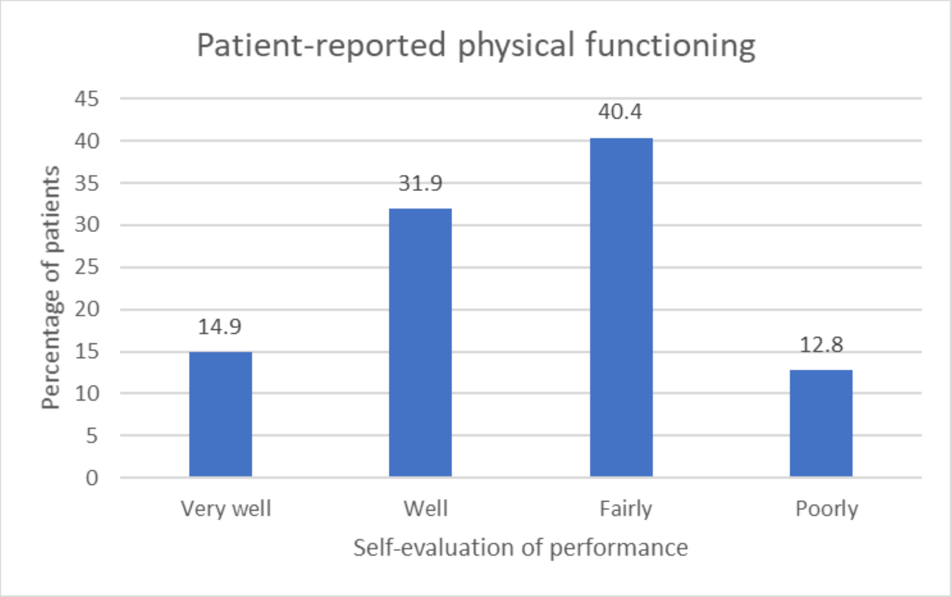
Based on survey responses from 47 patients with systemic lupus erythematosus; assessed on a Likert scale, scored 1-5, with higher scores representing greater difficulty.



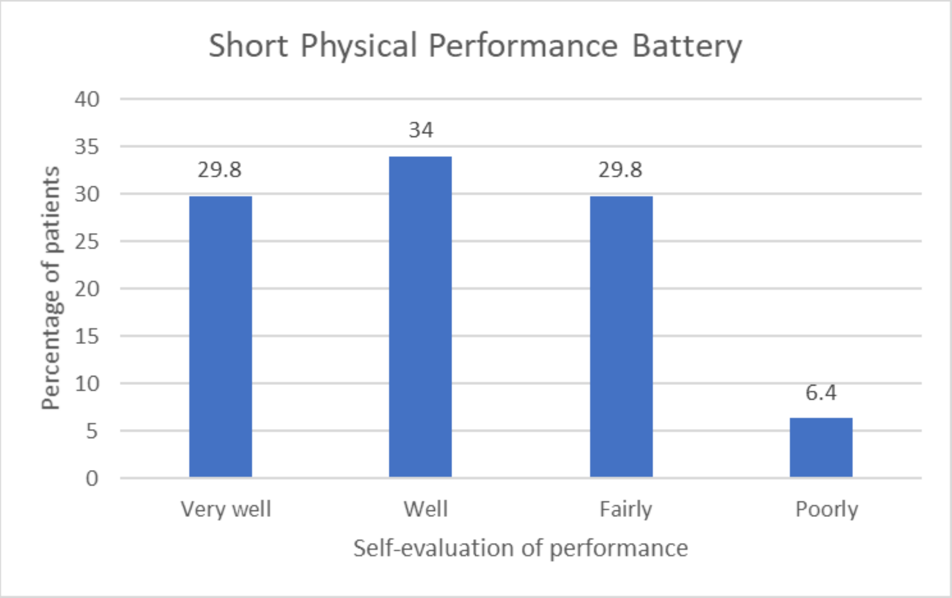
Part A. Self-evaluation of performance for the activities of daily living.



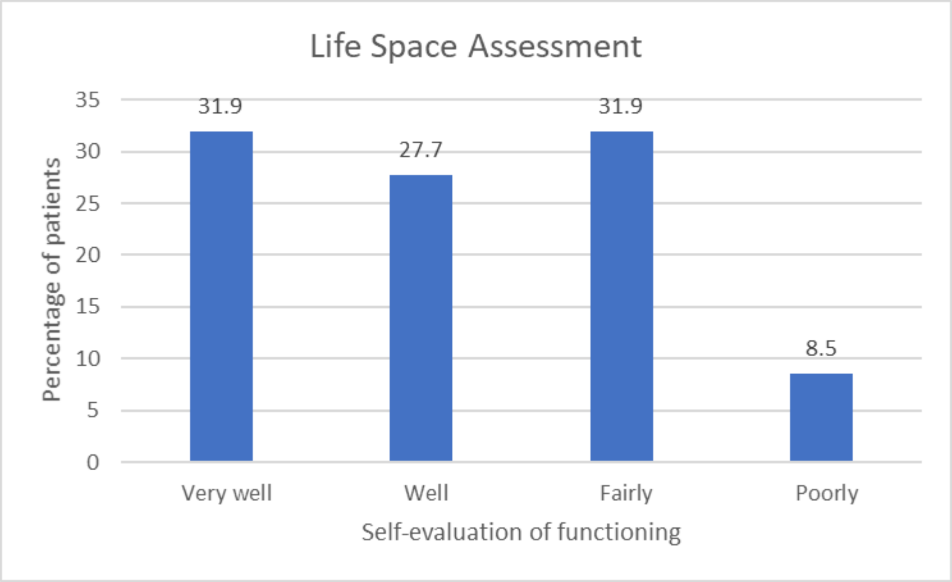
Part B. Self-evaluation of performance for falls.



Part C. Self-evaluation of performance for patient-reported physical functioning.



Part D. Self-evaluation of performance for the Short Physical Performance Battery.



Part E. Self-evaluation of performance for the Life Space Assessment.

Overall review of report

Table 4. Summary of other feedback on report, by domain of functioning.

	Activities of Daily Living	Falls	Patient-reported physical functioning	Short Physical Performance Battery	Life Space Assessment
Recall answering questions on ability to perform tasks	41 (87.2%)	39 (82.3%)	43 (91.5%)	43 (91.5%)	42 (89.4%)
Utility of Report[a]	32 (68.1%)	30 (63.8%)	35 (74.5%)	35 (74.5%)	30 (63.8%)
Coherence of Report[b]					
Scale	43 (91.5%)	--	42 (89.4%)	41 (87.2%)	--
Scoring	44 (93.2%)	--	41 (87.2%)	41 (87.2%)	--
Colors	47 (100%)	--	47 (100%)	47 (100%)	46 (97.9%)
Wording	45 (95.7%)	45 (95.7%)	46 (97.9%)	--	44 (93.2%)
Numbers	--	42 (89.4%)	--	--	--
Picture	--	--	--	47 (100%)	46 (97.9%)
Chart	--	--	--	--	39 (82.3%)
Comfort with discussion of report (yes vs. no)	46 (97.9%)	44 (93.2%)	47 (100%)	44 (93.2%)	44 (93.2%)
Comfort with discussion of report with:[c]					
Rheumatologist	32 (68.1%)	29 (61.7%)	34 (72.3%)	32 (68.1%)	29 (61.7%)
Primary Care Provider	25 (53.2%)	19 (40.4%)	26 (55.3%)	21 (44.7%)	19 (40.4%)
Social Worker	5 (10.6%)	4 (8.5%)	5 (10.6%)	3 (6.4%)	4 (8.5%)
Physical Therapist	7 (14.9%)	7 (14.9%)	7 (14.9%)	7 (14.9%)	8 (17.0%)
Occupational Therapist	3 (6.4%)	4 (8.5%)	4 (8.5%)	3 (6.4%)	3 (6.4%)
Psychiatrist	4 (8.5%)	2 (4.3%)	1 (2.1%)	2 (4.3%)	3 (6.4%)
Other provider	6 (12.8%)	7 (14.9%)	8 (17.0%)	8 (17.0%)	7 (14.9%)
Spouse	7 (14.9%)	7 (14.9%)	7 (14.9%)	5 (10.6%)	6 (12.8%)
Child	7 (14.9%)	5 (10.6%)	7 (14.9%)	6 (12.8%)	6 (12.8%)
Other relative	8 (17.0%)	9 (19.2%)	9 (19.2%)	6 (12.8%)	7 (14.9%)

Purpose in Discussion					
Improve communication with provider	28 (59.6%)	23 (48.9%)	30 (63.8%)	29 (61.7%)	27 (57.5%)
Obtain needed referrals and services	9 (19.2%)	11 (23.4%)	13 (27.7%)	10 (21.3%)	11 (23.4%)
Work on improving functioning	30 (63.8%)	15 (31.9%)	22 (46.8%)	22 (46.8%)	19 (40.4%)
Set treatment goals	16 (34.0%)	14 (29.8%)	16 (34.0%)	20 (42.6%)	16 (34.0%)

[a] Utility of Report: Number of participants who indicated that they perceived the report to be "useful for treatment or other personal care planning."

[b] Coherence of Report: Number of participants who indicated that it was "very easy" or "somewhat easy" in interpreting the overall report. Subsections represent the number of participants who indicated that they had "no difficulty" in interpreting the respective portion of the report.

[c] Comfort with discussion of report: Number of participants who indicated that they "felt comfortable discussing the report" with healthcare providers or other individuals.

Table 5. Feedback on potential use of report.

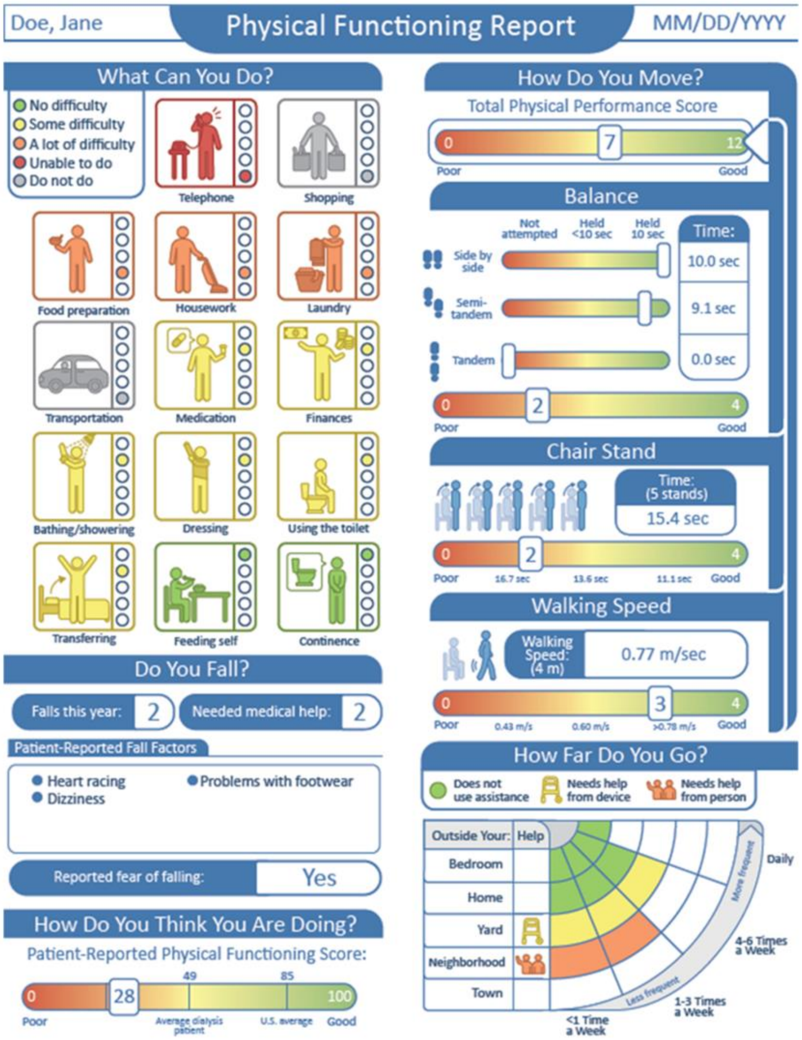
Item	**N (%)**
Interest in receiving real-time report	41 (87.2%)
Willingness to arrive early to appointments to perform physical tests and complete surveys	41 (87.2%)
Frequency of performing physical tests and completing surveys to receive report	
Monthly	8 (17.0%)
Every 3 months	17 (36.2%)
Every 6 months	12 (25.5%)
Yearly	7 (14.9%)
Never	1 (2.1%)
Other	2 (4.3%)

Appendix

Feedback Survey: A Physical Functioning Report for Lupus Patients

Thank you for agreeing to participate in our study.

We are interested in your thoughts on the physical functioning reports we have developed. Here is an example report.



Doe, Jane
Physical Functioning Report
MM/DD/YYYY

What Can You Do?
No difficulty
Some difficulty
A lot of difficulty
Unable to do
Do not do
Telephone
Shopping
Food preparation
Housework
Laundry
Transportation
Medication
Finances
Bathing/showering
Dressing
Using the toilet
Transferring
Feeding self
Continence

Do You Fall?
Falls this year: 2
Needed medical help: 2
Patient-Reported Fall Factors
- Heart racing
- Dizziness
- Problems with footwear

Reported fear of falling: Yes

How Do You Think You Are Doing?
Patient-Reported Physical Functioning Score: 28
0 Poor — 49 Average dialysis patient — 85 U.S. average — 100 Good

How Do You Move?
Total Physical Performance Score: 7
0 Poor — 12 Good

Balance
Not attempted — Held <10 sec — Held 10 sec — Time:
Side by side: 10.0 sec
Semi-tandem: 9.1 sec
Tandem: 0.0 sec
2 (0 Poor — 4 Good)

Chair Stand
Time: (5 stands) 15.4 sec
2 (0 Poor — 16.7 sec — 13.6 sec — 11.1 sec — 4 Good)

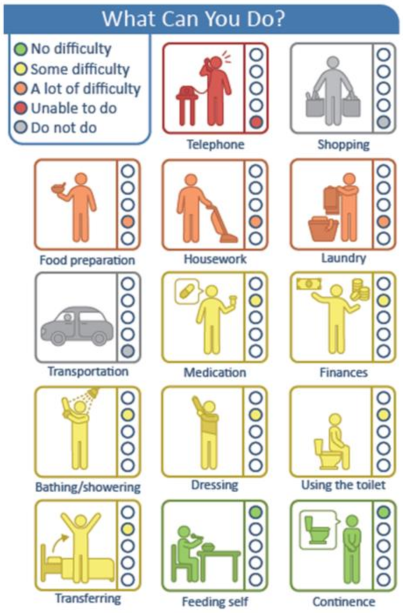
Walking Speed
Walking Speed: (4 m) 0.77 m/sec
3 (0 Poor — 0.43 m/s — 0.60 m/s — >0.78 m/s — 4 Good)

How Far Do You Go?
Does not use assistance
Needs help from device
Needs help from person

Outside Your:	Help
Bedroom	
Home	
Yard	Needs help from device
Neighborhood	Needs help from person
Town	

To complete this survey, you will need your personalized report, which was sent to you by email or mail. This report shows you the results from your visit for the APPEAL pilot study, which took place between October 2016 and April 2017. <u>Looking at the personalized report you received, please answer the questions on the following pages</u>.

To start, please find the part of your report that says "What Can You Do?," which looks like this:



Look at <u>your</u> results in this part of the report to answer the next few questions.

1. Do you remember answering questions during the pilot study about whether you could perform these tasks (circle one)?

Yes No

2. How well do you think you were performing these tasks (check one)?

☐ Very well

☐ Well

☐ Fairly

☐ Poorly

3. How easy is it to understand your results (check one)?

☐ Very easy (skip to question 6)

☐ Somewhat easy

☐ Neither easy nor difficult

☐ Somewhat difficult

☐ Very difficult

4. What part(s) are difficult to understand (check all that apply)?

☐ Pictures

☐ Wording

☐ Colors

☐ Other (list:___________________________________)

5. Please share any ideas you have to make this part of the report easier to understand.

6. Do you think it would be useful for your treatment or other personal care planning to discuss this part of the report with anyone (circle one)?

Yes No (skip to question 9)

7. With whom would you want to discuss this part of your report (check all that apply)?

☐ Rheumatologist/lupus doctor

☐ Primary care provider

☐ Social worker

☐ Physical therapist

☐ Occupational therapist

☐ Psychiatrist/psychologist/therapist

☐ Other healthcare provider (list: ________________________________)

☐ Spouse

☐ Child

☐ Other relative

☐ Friend

☐ Spiritual or religious advisor

☐ Employer

☐ Other (list:___________________________________)

8. Why would you discuss this part of the report (check all that apply)?

☐ To have better communication/relationship with providers

☐ To get needed referrals/services

☐ To work on improving my function

☐ To help set treatment goals

☐ Other (list:___________________________________)

9. Would you feel comfortable discussing these tasks with your providers (circle one)?

Yes No

Now please look at the part of your report that says "Do You Fall?," which looks like this:

Do You Fall?

Falls this year: 2

Needed medical help: 2

Patient-Reported Fall Factors

Not measured

Reported fear of falling: Yes

Look at <u>your</u> results in this part of the report to answer the next few questions.

10. Do you remember answering questions during the pilot study about whether you had fallen in the past year, and how confident you were that you would not fall during daily tasks (circle one)?

Yes No

11. How well do you think you were doing in terms of falls (check one)?

☐ Very well

☐ Well

☐ Fairly

☐ Poorly

12. How easy is it to understand your results (check one)?

☐ Very easy (skip to question 15)

☐ Somewhat easy

☐ Neither easy nor difficult

☐ Somewhat difficult

☐ Very difficult

13. What part(s) are difficult to understand (check all that apply)?

☐ Wording

☐ Numbers

☐ Other (list:___________________________________)

14. Please share any ideas you have to make this part of the report easier to understand.

15. Do you think it would be useful for your treatment or other personal care planning to discuss this part of the report with anyone (circle one)?

Yes No (skip to question 18)

16. With whom would you want to discuss this part of your report (check all that apply)?

☐ Rheumatologist/lupus doctor

☐ Primary care provider

☐ Social worker

☐ Physical therapist

☐ Occupational therapist

☐ Psychiatrist/psychologist/therapist

☐ Other healthcare provider (list: _______________________________)

☐ Spouse

☐ Child

☐ Other relative

☐ Friend

☐ Spiritual or religious advisor

☐ Employer

☐ Other (list:___________________________________)

17. Why would you discuss this part of the report (check all that apply)?

☐ To have better communication/relationship with providers

☐ To get needed referrals/services

☐ To work on improving my function

☐ To help set treatment goals

☐ Other (list:___________________________________)

18. Would you feel comfortable discussing your falls or fear of falling with your providers (circle one)?

Yes No

Now please look at the part of your report that says "How Do You Think You Are Doing?," which looks like this:

Look at <u>your</u> results in this part of the report to answer the next few questions.

19. Do you remember answering questions during the pilot study in how much your health limited you in physical activities (circle one)?

Yes No

20. How well did you think you were doing with physical activities (check one)?

☐ Very well

☐ Well

☐ Fairly

☐ Poorly

21. How easy is it to understand your results (check one)?

☐ Very easy (skip to question 24)

☐ Somewhat easy

☐ Neither easy nor difficult

☐ Somewhat difficult

☐ Very difficult

22. What part(s) are difficult to understand (check all that apply)?

☐ Scale (poor to good)

☐ Score

☐ Colors

☐ Wording

☐ Other (list:___________________________________)

23. Please share any ideas you have to make this part of the report easier to understand.

24. Do you think it would be useful for your treatment or other personal care planning to discuss this part of the report with anyone (circle one)?

Yes No (skip to question 27)

25. With whom would you want to discuss this part of your report (check all that apply)?

☐ Rheumatologist/lupus doctor

☐ Primary care provider

☐ Social worker

☐ Physical therapist

☐ Occupational therapist

☐ Psychiatrist/psychologist/therapist

☐ Other healthcare provider (list: _______________________________)

☐ Spouse

☐ Child

☐ Other relative

☐ Friend

☐ Spiritual or religious advisor

☐ Employer

☐ Other (list:___________________________________)

26. Why would you discuss this part of the report (check all that apply)?

☐ To have better communication/relationship with providers

☐ To get needed referrals/services

☐ To work on improving my function

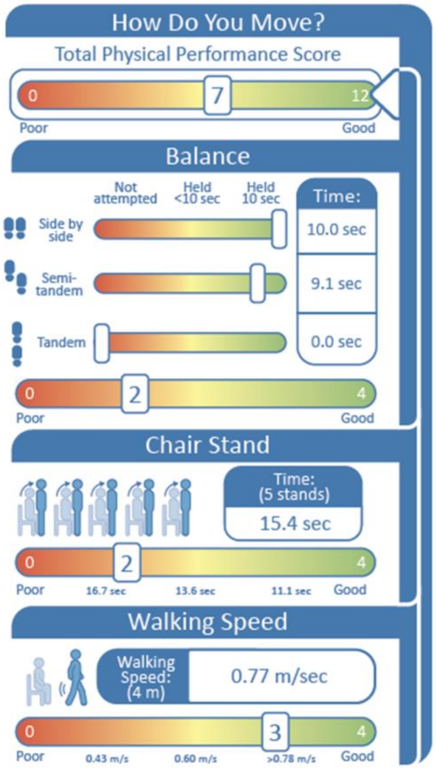
☐ To help set treatment goals

☐ Other (list:___________________________________)

27. Would you feel comfortable discussing how much you feel limited in your physical activities with your providers (circle one)?

Yes No

Now please look at the part of your report that says "How Do You Move?," which looks like this:



Look at <u>your</u> results in this part of the report to answer the next few questions.

28. Do you remember being asked to perform these tests (balance, walking, standing from a chair) (circle one)?

Yes No

29. How well do you think do you think you did on these tests (check one)?

☐ Very well

☐ Well

☐ Fairly

☐ Poorly

30. How easy is it to understand your results (check one)?

☐ Very easy (skip to question 33)

☐ Somewhat easy

☐ Neither easy nor difficult

☐ Somewhat difficult

☐ Very difficult

31. What part(s) are difficult to understand (check all that apply)?

☐ Scales (poor to good)

☐ Pictures

☐ Scores

☐ Colors

☐ Wording

☐ Other (list:___________________________________)

32. Please share any ideas you have to make this part of the report easier to understand.

33. Do you think it would be useful for your treatment or other personal care planning to discuss this part of the report with anyone (circle one)?

Yes No (skip to question 36)

34. With whom would you want to discuss this part of your report (check all that apply)?

☐ Rheumatologist/lupus doctor

☐ Primary care provider

☐ Social worker

☐ Physical therapist

☐ Occupational therapist

☐ Psychiatrist/psychologist/therapist

☐ Other healthcare provider (list: ________________________________)

☐ Spouse

☐ Child

☐ Other relative

☐ Friend

☐ Spiritual or religious advisor

☐ Employer

☐ Other (list:___________________________________)

35. Why would you discuss this part of the report with providers (check all that apply)?

☐ To have better communication/relationship with providers

☐ To get needed referrals/services

☐ To work on improving my function

☐ To help set treatment goals

☐ Other (list:___________________________________)

36. Would you feel comfortable discussing how you did on these tests with your providers (circle one)?

Yes No

Now please look at the part of your report that says "How Far Do You Go?," which looks like this:

Look at <u>your</u> results in this part of the report to answer the next few questions.

37. Do you remember being asked questions during the pilot study about how far you go outside your bedroom, how often, and with how much help (circle one)?

Yes No

38. How well do you think you were moving around in your home, neighborhood, and community (check one)?

☐ Very well

☐ Well

☐ Fairly

☐ Poorly

39. How easy is it to understand your results (check one)?

☐ Very easy (skip to question 42)

☐ Somewhat easy

☐ Neither easy nor difficult

☐ Somewhat difficult

☐ Very difficult

40. What part(s) are difficult to understand (check all that apply)?

☐ Chart

☐ Pictures

☐ Colors

☐ Wording

☐ Other (list:___________________________________)

41. Please share any ideas you have to make this part of the report easier to understand.

42. Do you think it would be useful for your treatment or other personal care planning to discuss this part of the report with anyone (circle one)?

Yes No (skip to question 45)

43. With whom would you want to discuss this part of your report (check all that apply)?

☐ Rheumatologist/lupus doctor

☐ Primary care provider

☐ Social worker

☐ Physical therapist

☐ Occupational therapist

☐ Psychiatrist/psychologist/therapist

☐ Other healthcare provider (list: ________________________________)

☐ Spouse

☐ Child

☐ Other relative

☐ Friend

☐ Spiritual or religious advisor

☐ Employer

☐ Other (list:___________________________________)

44. Why would you discuss this part of the report (check all that apply)?

☐ To have better communication/relationship with providers

☐ To get needed referrals/services

☐ To work on improving my function

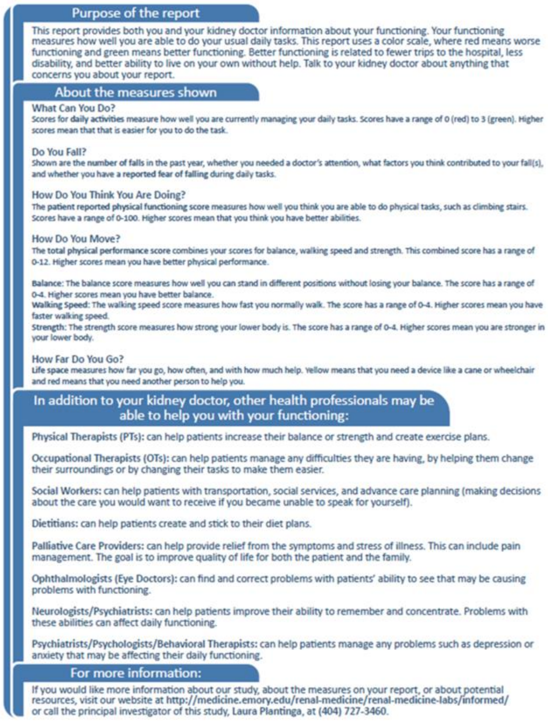
☐ To help set treatment goals

☐ Other (list:___________________________________)

45. Would you feel comfortable discussing how well you are moving around in your community with your providers (circle one)?

Yes No

Now please look at the back of your report, which looks like this:



Purpose of the report

This report provides both you and your kidney doctor information about your functioning. Your functioning measures how well you are able to do your usual daily tasks. This report uses a color scale, where red means worse functioning and green means better functioning. Better functioning is related to fewer trips to the hospital, less disability, and better ability to live on your own without help. Talk to your kidney doctor about anything that concerns you about your report.

About the measures shown

What Can You Do?
Scores for **daily activities** measure how well you are currently managing your daily tasks. Scores have a range of 0 (red) to 3 (green). Higher scores mean that that is easier for you to do the task.

Do You Fall?
Shown are the **number of falls** in the past year, whether you needed a doctor's attention, what factors you think contributed to your fall(s), and whether you have a **reported fear of falling** during daily tasks.

How Do You Think You Are Doing?
The **patient reported physical functioning score** measures how well you think you are able to do physical tasks, such as climbing stairs. Scores have a range of 0-100. Higher scores mean that you think you have better abilities.

How Do You Move?
The **total physical performance score** combines your scores for balance, walking speed and strength. This combined score has a range of 0-12. Higher scores mean you have better physical performance.

Balance: The balance score measures how well you can stand in different positions without losing your balance. The score has a range of 0-4. Higher scores mean you have better balance.
Walking Speed: The walking speed score measures how fast you normally walk. The score has a range of 0-4. Higher scores mean you have faster walking speed.
Strength: The strength score measures how strong your lower body is. The score has a range of 0-4. Higher scores mean you are stronger in your lower body.

How Far Do You Go?
Life space measures how far you go, how often, and with how much help. Yellow means that you need a device like a cane or wheelchair and red means that you need another person to help you.

In addition to your kidney doctor, other health professionals may be able to help you with your functioning:

Physical Therapists (PTs): can help patients increase their balance or strength and create exercise plans.

Occupational Therapists (OTs): can help patients manage any difficulties they are having, by helping them change their surroundings or by changing their tasks to make them easier.

Social Workers: can help patients with transportation, social services, and advance care planning (making decisions about the care you would want to receive if you became unable to speak for yourself).

Dietitians: can help patients create and stick to their diet plans.

Palliative Care Providers: can help provide relief from the symptoms and stress of illness. This can include pain management. The goal is to improve quality of life for both the patient and the family.

Ophthalmologists (Eye Doctors): can find and correct problems with patients' ability to see that may be causing problems with functioning.

Neurologists/Psychiatrists: can help patients improve their ability to remember and concentrate. Problems with these abilities can affect daily functioning.

Psychiatrists/Psychologists/Behavioral Therapists: can help patients manage any problems such as depression or anxiety that may be affecting their daily functioning.

For more information:

If you would like more information about our study, about the measures on your report, or about potential resources, visit our website at **http://medicine.emory.edu/renal-medicine/renal-medicine-labs/informed/** or call the principal investigator of this study, **Laura Plantinga, at (404) 727-3460.**

46. How easy is it to understand this information (check one)?

☐ Very easy

☐ Somewhat easy

☐ Neither easy nor difficult

☐ Somewhat difficult

☐ Very difficult

47. How helpful is this information (check one)?

☐ Very helpful

☐ Somewhat helpful

☐ Neither helpful nor unhelpful

☐ Somewhat unhelpful

☐ Very unhelpful

48. Is there anything that could be included that would make the back of the report easier or more helpful?

Finally, we would like to know your thoughts about the report as a whole, and how useful it might be in your lupus care.

49. Is there anything else *not* included on the report that you would want your provider to know about your functioning?

50. Would you be interested in getting a report like this in real time (in other words, on the same day as it is measured) (circle one)?

Yes No

51. Would you be willing to arrive 20-30 minutes before doctor appointments to perform the physical tests and fill out surveys, so that you and your provider could each have a copy of your report during the appointment (circle one)?

Yes No

52. If this report were offered as part of your usual lupus care, how often would you be willing to do 20-30 minutes of performance tests (for example, walking speed) and surveys to receive this personalized report?

☐ Once a month

☐ Every 3 months

☐ Every 6 months

☐ Once a year

☐ Never

☐ Other (list:_________________________________)

Thank you again for your participation in our APPEAL study, which is helping to guide current research in improving lupus care.

If you have any questions about this study or the report, please do not hesitate to contact the study coordinator, Charmayne Dunlop-Thomas (cmdunlo@emory.edu, 404-251-8898), or the principal investigator, Dr. Laura Plantinga (laura.plantinga@emory.edu, 404-727-3460).

APPEAL

GOAL
GEORGIANS ORGANIZED AGAINST LUPUS

Supplementary Information

Abbreviations

APPEAL: Approaches to Positive, Patient-centered Experiences of Aging in Lupus; BADL: Basic Activity of Daily Living; GOAL: Georgians Organized Against Lupus cohort; HRQOL: Health-Related Quality of Life; IADL: Instrumental Activity of Daily Living; INFORMED: INstant Functional Outcomes Report for Meaningful Encounters in Dialysis; LSA: Life-Space Assessment; SF-36: Medical Outcome Short Study Form-36 Health Survey; PRO: Patient Reported Outcomes; PF: Physical Functioning.

Funding

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Ethics Approval and Consent to Participate

This study was approved by the Emory University Institutional Review Board (protocol no. IRB00104581). Written informed consent was obtained from all pilot study participants.