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## How Should Disability Be Measured in Older Adults? An Analysis from the Boston Rehabilitative Impairment Study of the Elderly

Marla K. Beauchamp, PhD<sup>1,2,3</sup>, Jonathan F. Bean, MD<sup>1,2</sup>, Rachel E. Ward, PhD<sup>1,2,3</sup>, Laura A. Kurlinski, BA<sup>2</sup>, Nancy K. Latham, PhD<sup>3</sup>, and Alan M. Jette, PhD<sup>3</sup>

<sup>1</sup> Department of Physical Medicine and Rehabilitation, Harvard Medical School, Cambridge, Massachusetts

<sup>2</sup> Spaulding Rehabilitation Hospital, Boston, Massachusetts

<sup>3</sup> Health and Disability Research Institute, Boston University School of Public Health, Boston, Massachusetts

## Abstract

**Objectives**—The Late-Life Function and Disability Instrument (LLFDI) assesses two key dimensions of disability: frequency of and limitations in performance of major life tasks. The aim of this study was to determine and compare the predictive validity and responsiveness of the LLFDI frequency and limitation dimensions.

**Design**—Secondary analysis of 2-year follow-up data from the Boston Rehabilitative Impairment Study of the Elderly (RISE).

Setting—Primary care.

**Participants**—Community-dwelling older adults (age 65 years) (n=430) at risk for mobility decline.

**Measurements**—The LLFDI frequency and limitation dimensions, self-rated health, hospitalizations and emergency room (ER) visits over 2 years. Responsiveness measures included effect size (ES) estimates and minimal detectable change (MDC) scores.

**Corresponding author:** Marla K Beauchamp, PT, PhD, Department of Physical Medicine and Rehabilitation , Harvard Medical School, Spaulding Outpatient Center Cambridge,1575 Cambridge St., Cambridge, MA 02138, mkbeauchamp@partners.org, Phone: 617 952-6954, Fax: 617-952-6965.

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**Conflicts of Interest:** Alan M. Jette has stock holdings in CREcare, LLC, a small business created to disseminate outcome instruments such as the LLFDI. The authors have no other conflicts of interest to declare.

**Results**—The LLFDI frequency dimension predicted low self-rated health (OR =0.51, P <.001), hospitalizations (OR =0.68, P <.001), and ER visits (OR =0.73, P =0.003) over 2 years while the limitation dimension did not. The absolute ES was 0.63 for the frequency dimension and 0.81 for the limitation dimension. The proportion of subjects with a decline the MDC was 10.6% for the frequency dimension and 14.2% for the limitation dimension. For patients who improved the MDC, the proportion was 1.7% for the frequency dimension and 15.3% for the limitation dimension.

**Conclusion**—Frequency of participation in major life roles was a better predictor of adverse outcomes than perceived limitations; however, limitations appeared to be more responsive to meaningful change. These results can be used to guide the selection of the most appropriate metric for measuring disability in geriatric research.

#### Keywords

Disability; community-dwelling older adults; minimal detectable change; responsiveness; validity

## INTRODUCTION

Although disability is recognized as a critical outcome in geriatric research, it remains difficult to measure. There is considerable variability in the definition of disability; some studies define disability in terms of discrete functional deficits such as limitations in mobility or performance of basic activities of daily living, while others use broader indicators such as performance of socially defined life activities. This lack of conceptual clarity limits progress in both understanding the disablement process and in demonstrating important changes in disability after interventions.

In 2002, the Late-Life Function and Disability Instrument (LLFDI) was developed to address these limitations.<sup>1, 2</sup> The LLFDI is a patient-reported outcome measure that assesses functional limitations and disability based on an explicit theoretical framework.<sup>3</sup> Consistent with Nagi's disablement model, disability within the LLFDI refers to a person's performance of socially defined life tasks within his or her environment. This definition is also consistent with the concept of participation restrictions in the World Health Organization's International Classification of Functioning, Disability, and Health (ICF).<sup>4</sup> One of the unique features of the LLFDI is that it considers two important dimensions of disability: frequency of performance of life activities and limitations in a person's capability to perform each activity.

Over the last decade, the LLFDI has been used in studies involving more than 17,000 older adults with extensive evidence supporting its construct validity.<sup>5</sup> A recent systematic review<sup>5</sup> confirmed the sensitivity to change of the disability limitation dimension, but there was limited data on the frequency dimension and no studies on predictive validity of either disability dimension. Therefore, the objective of this study was to determine and compare the predictive validity and responsiveness of the LLFDI disability frequency and limitation dimensions in a cohort of older primary care patients. We hypothesized that both dimensions would show similarly high predictive validity for adverse outcomes and responsiveness to change over 2 years.

## **METHODS**

#### **Participants**

We performed a secondary analysis of baseline and 2-year follow-up data from the Boston Rehabilitative Impairment Study of the Elderly (Boston RISE), a longitudinal cohort study of 430 older adults at risk for mobility decline.

Methods for Boston RISE were approved by the relevant Institutional Review Boards and study details have been published previously.<sup>6</sup> Participants were recruited from primary care practices in the Greater Boston Area. Inclusion criteria comprised: age 65 years, ability to speak and understand English, self-reported difficulty or task modification with walking <sup>1</sup>/<sub>2</sub> mile and/or climbing 1 flight of stairs, no planned major surgery and expectation of living in the area for 2 years. Exclusion criteria were: significant visual impairment, uncontrolled hypertension, lower-extremity amputation, supplemental oxygen use, myocardial infarction or major surgery in the previous 6 months, Mini Mental State Exam score <18 and Short Physical Performance Battery score <4. Baseline assessments were conducted over 2 visits and repeated annually for 2 years. Study staff contacted participants by phone every 3 months to track health care utilization.

#### Measures

Late-Life Function and Disability Instrument (LLFDI)—The LLFDI is a patientreported measure that assesses both functional limitations and disability. Questionnaire items for the LLFDI were developed and refined based on the Nagi<sup>3</sup> and ICF<sup>4</sup> disablement models, review of existing instruments, consultation with experts, and focus groups with older adults. Exploratory factor analysis and Rasch analysis were used to further refine the LLFDI and to develop the subscales. This investigation focused on the Disability component which assesses an older person's frequency of participation in 16 major life tasks and the person's limitation in his/her capability to perform each task. Frequency dimension questions are phrased, "How often do you" do a specific task with response options of "very often", "often", "once in a while", "almost never" and "never". Limitation dimension questions are phrased "To what extent do you feel limited in" doing the same task with response options of "not at all", "a little", "somewhat", "a lot", and "completely". The frequency dimension is further broken down into a social role domain (includes social and community tasks such as keeping in touch with others and taking part in active recreation) and a personal role domain (includes personal tasks such as taking care of the home and personal health). Similarly, within the limitation dimension are the instrumental role domain (includes home or community activities such as taking care of the home and taking part in active recreation) and the management role domain (includes organizational tasks that require minimal mobility such as keeping in touch with others and taking care of personal health). For a full description of items please see Jette et al.<sup>2</sup> Raw scores for each dimension and subscale are transformed to scaled scores (0-100) based on a Rasch model with higher scores indicating less disability. Evidence supports the LLFDI's construct validity, sensitivity to change and reliability among older adults.<sup>1, 2, 5</sup>

**Self-rated health and self-reported walking difficulty**—Self-rated health was determined using a 5-point Likert scale in response to the question "In general, how would you say your health is?";<sup>7</sup> a response of poor or fair was used to categorize those with low self-rated health at 2 years. Self-reported walking difficulty was determined in response to the question "Do you have difficulty walking a half mile?" with response of yes or no.<sup>8</sup> Both self-rated health and self-reported walking difficulty are predictive of mortality and health-care utilization.<sup>9-11</sup>

**Short Physical Performance Battery (SPPB)**—The SPPB is a performance-based test comprised of 3 components: standing balance, usual pace walking speed and a 5-repetition chair stand test. Scores from each component are added to create a summary score between 0-12, with higher scores indicating better performance. A 1-point change in SPPB score is predictive of mortality and nursing home admissions.<sup>12</sup>

**Hospitalizations and emergency room visits**—Hospitalizations (defined as an overnight hospital stay for any reason) and emergency room visits were recorded from standardized questions administered by telephone every 3 months and as part of the yearly in-person assessment.

#### Statistical Analyses

**Predictive validity**—Separate logistic regression models were constructed to assess each LLFDI disability scale as a predictor of: 1) low self-rated health at 2 years; 2) one or more hospitalizations over 2 years; and 3) one or more emergency room visits over 2 years. The increased odds of having an unfavorable outcome for a 1SD change in each scale were calculated. Models were adjusted for age and gender. Data analyses were performed using SAS version 9.3 (SAS Institute, Inc., Cary, NC).

**Responsiveness**—In this study, we defined responsiveness as the degree to which a measure detects meaningful change. To determine meaningful change use of both distribution-based methods (i.e., statistical distributions of change and associated reliability) and anchor-based methods (i.e., external criterion of change reflecting a patient or clinician's perspective) is recommended.<sup>14</sup> The following responsiveness metrics were calculated for each LLFDI Disability scale:

- 1) Absolute effect sizes (ES) were computed as  $ES=abs((M_2-M_1))/S_b$ , where  $M_2$  is the mean score at year 2,  $M_1$  is the mean score at baseline, and  $S_b$  is the standard deviation at baseline. We used absolute ES to provide a metric of responsiveness independent of direction because some variability in the trajectories of change was anticipated (i.e., some participants might improve while others decline). Values of 0.20, 0.50, and 0.80 are considered small, moderate and large effect sizes, respectively.<sup>15</sup>
- 2) The ES for each scale was also computed for subgroups of patients using external criteria to categorize those who either declined or improved in self-rated health, SPPB score, and self-reported walking difficulty.

- 3) To provide a value for measurement error in the same units as the LLFDI, the standard error of the measurement (SEM) was calculated as  $SEM = S_b^*$  (1-r), where  $S_b$  is the standard deviation at baseline and r is the test-retest reliability coefficient. Data for the reliability coefficients were obtained from previous work.<sup>2</sup>
- Minimal detectable change scores with 90% confidence were calculated as (MDC<sub>90</sub>) = SEM\*1.645\*sqrt2.<sup>16</sup> The MDC<sub>90</sub> corresponds to the smallest amount of change that can be considered true change that falls outside of measurement error. The percentages of patients who demonstrated a decline/ improvement the MDC<sub>90</sub> over 2 years were calculated for each scale.

## RESULTS

At baseline, 430 Boston RISE participants had a mean age of 77 years and 68% were female. The sample was predominately white (82.6%) with an average of 4.0 (SD 1.9) chronic conditions and a mean baseline SPPB score of 8.7 (SD 2.3). The mean score on the LLFDI disability frequency dimension was 52.3 (SD 5.7) with no ceiling or floor effects; the mean score on the disability limitation dimension was 68.9 (SD 11.8) with no floor effects but 6.5% at the ceiling (data not shown in tables).

At 2 years, 360 participants remained in the study. Sample sizes for the individual analyses varied based on the methods and outcomes used. Of the 276 participants with data on patient-reported health status at 2 years, 56 (20.3%) reported low self-rated health. Quarterly phone call data were available on 427 participants for hospitalizations and 423 for emergency room visits; 164 (38.4%) reported one or more hospitalizations and 201 (47.5%) reported one or more emergency room visits over 2 years.

#### **Predictive validity**

The logistic regression models that show the odds of having an unfavorable outcome for every 1 SD increase in LLFDI score, adjusted for age and gender, are presented in Table 1. The LLFDI summary frequency dimension and personal and social role subscales showed high predictive validity for low self-rated health and hospitalizations. The summary frequency dimension and personal role subscale were also predictive of emergency visits over 2 years. The summary limitation dimension and subscales were generally not statistically significant predictors of adverse outcomes; with the exception of the management role subscale which predicted low self-rated health. There was also a trend for some predictive value with the instrumental role subscale for low self-rated health (P = .06), and with overall limitation and instrumental role subscales for hospitalizations (P = .08 and P= .06, respectively).

#### Responsiveness

Results of the responsiveness analysis are shown in Table 2. Larger absolute ES (0.75-0.83) were observed for the LLFDI limitation summary scale and subscales, whereas moderate ES (0.57-0.67) were noted for frequency dimension summary scale and subscales.

When we sub-categorized participants based on improvement in self-rated health, SPPB score and self-reported walking ability over 2 years, the LLFDI limitation scales demonstrated larger positive ES in all three categories compared with the disability frequency scales (Table 2). Larger negative ES were also noted for the limitation scales among those who declined in self-rated health, whereas the frequency dimension scales showed larger negative ES among those who declined in the functional criteria (SPPB and self-reported walking ability).

The percentages of participants demonstrating a change the MDC<sub>90</sub> for each scale are shown in Table 2. Overall, the greatest proportion of participants with a meaningful change in disability in either direction was found for the limitation in instrumental role domain (32.0% changed 12.4 points). Figure 1 shows the proportion of participants with a decline (1A) or improvement (1B) on each LLFDI scale based on their individually determined MDC<sub>90</sub> value in Table 2. The proportion of participants who declined the MDC<sub>90</sub> was largest for the instrumental role and overall limitation domain (14.2-16.8%), followed by the overall frequency dimension and social role domain (both 10.56%) (Figure 1A). Improvement the MDC<sub>90</sub> was highest for the overall limitation dimension and instrumental role domain (both 15.3%), with considerably less responsiveness for the other scales (all <5%) (Figure 1B).

## DISCUSSION

Our findings highlight the important distinction between frequency of and limitations in participation in major life activities for disability measurement. Choices about which component of multidimensional disability scales to use in geriatric research should be based on the objectives of the study and the best available evidence for a particular metric's psychometric properties.

To our knowledge this is the first study to evaluate the predictive validity of the disability component of the LLFDI. Our findings demonstrated that reported frequency of performing life activities, particularly personal tasks, had high predictive validity for low self-rated health, emergency room visits, and hospitalizations over 2 years. In contrast, reported limitation in performing major life roles had limited predictive value. This was an unexpected and noteworthy finding, especially since most generic disability measures are focused on what a patient "can do" and very few include questions regarding what a patient "does do".<sup>17, 18</sup> While there was a small ceiling effect with the limitation dimension (6.5% scored 100 at baseline), this alone is likely not enough to account for the contrasting results. As such, the frequency dimension of the LLFDI may prove a valuable indicator of disability for longitudinal investigations of the negative sequelae of the disablement process.

In a previous systematic review on the LLFDI,<sup>5</sup> we noted that intervention studies (primarily exercise-based) more commonly evaluated the limitation dimension than the frequency dimension and that the former was associated with larger relative effect sizes. Therefore, our finding of larger overall ES estimates for the limitation dimension and subscales are in line with previous work. In addition, while both dimensions appeared to be responsive to decline in the external anchors of perceived health status and function, the limitation dimension,

particularly the instrumental role, was also responsive to improvement. We found similar results when we considered the percentages of patients who improved/declined above the  $MDC_{90}$  values. Of note, previous reviews of studies examining the effect of exercise interventions for improving disability in older adults have shown conflicting results.<sup>19-21</sup> It is possible that use of more responsive measures of disability would have resulted in more consistent conclusions; based on our findings, it appears that limitation in performing life tasks is more responsive to improvement than frequency of participation. This is perhaps not surprising, given that interventions that target changes in a person's capability are more easily achievable than changes in actual behavior.

This analysis should be interpreted in light of several limitations. Recall bias may have affected reporting of hospitalizations and emergency room visits. Our findings may not be generalizable to older adults residing outside the Boston area or those in other clinical settings. While we have presented  $MDC_{90}$  values for the LLFDI derived through distribution-based methods, we did not have a global measure of change in disability rated by the patient or clinician to use as a clinical anchor. This will be necessary to refine the estimation of the minimal clinically important difference for the LLFDI in future work.

In summary, we have shown that the frequency dimension of the LLFDI has high predictive validity for unfavorable outcomes and is responsive to decline over 2 years among community-dwelling older adults. We were unable to demonstrate the predictive validity of the limitation dimension; however, it appears this metric is responsive to both directions of change. These findings can be used to guide the selection of the most appropriate disability measure to address specific research questions in geriatric research.

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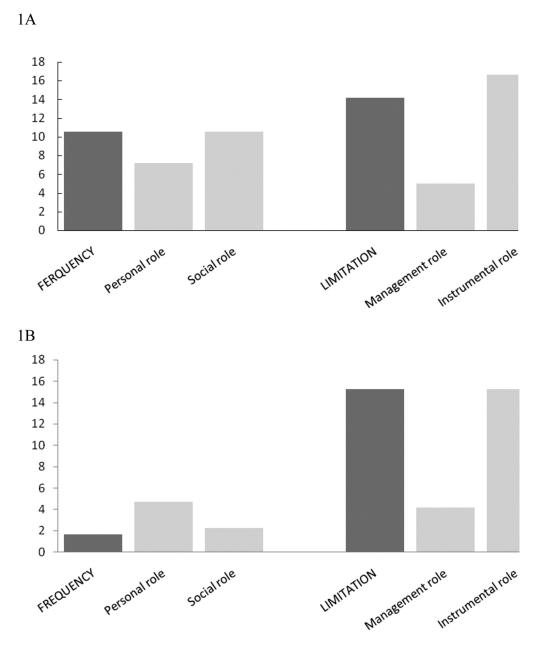
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#### Figure 1.

Comparison of percentages of participants demonstrating a decline (1A) or improvement (1B) the minimal detectable change ( $MDC_{90}$ ) over 2 years of follow-up on the Late-Life Function and Disability Instrument frequency and limitation dimensions and their subscales. For example, as shown in Figure 1B, 2% of participants improved the  $MDC_{90}$  of 7.4 points for the frequency dimension, compared to 15% of participants that improved the  $MDC_{90}$  of 11.6 points for the limitation dimension.

#### Table 1

	Low self-reported health (n=276)		Hospitalizations (n=427)		Emergency room visits (n=423)	
LLFDI scale	OR (95%CI)	P-value	OR (95%CI)	P-value	OR (95%CI)	P-value
Frequency	0.51 (0.36-0.73)	<.001	0.68 (0.55-0.84)	<.001	0.73 (0.60-0.90)	0.003
Personal role	0.66 (0.46-0.95)	0.025	0.68 (0.54-0.85)	<.001	0.73 (0.59-0.90)	0.003
Social role	0.53 (0.37-0.75)	<.001	0.82 (0.67-1.0)	0.047	0.85 (0.70-1.03)	0.096
Limitation	0.74 (0.53-1.04)	0.082	0.83 (0.68-1.02)	0.080	0.96 (0.79-1.17)	0.682
Management role	0.73 (0.54-0.99)	0.043	0.92 (0.75-1.12)	0.407	0.97 (0.80-1.18)	0.755
Instrumental role	0.72 (0.52-1.01)	0.060	0.82 (0.67-1.0)	0.057	0.95 (0.78-1.16)	0.624

Logistic regression models<sup>\*</sup> predicting adverse outcomes over 2 years

OR = odds ratio; CI = confidence interval

\* Models show the increased odds of having an adverse outcome for a 1 standard deviation increase in score on the Late-Life Function and Disability Instrument (LLFDI) adjusted for age and gender.

#### Table 2

## Responsiveness metrics over 2 years of follow-up\*

	Frequency	Personal role	Social role	Limitation	Management role	Instrumental role
Absolute ES	0.63	0.67	0.57	0.81	0.75	0.83
Decline in SRH ES (n=72)	-0.28	-0.09	-0.27	-0.45	-0.19	-0.51
Improvement in SRH ES (n=51)	-0.02	0.01	-0.01	0.37	0.01	0.39
Decline in SPPB ES (n=136)	-0.49	-0.25	-0.41	-0.19	-0.12	-0.23
Improvement in SPPB ES (n=149)	-0.15	-0.04	-0.17	0.12	0.02	0.12
Decline in walking ES (n=116)	-0.41	-0.33	-0.30	-0.19	-0.13	-0.21
Improvement in walking ES (n=109)	-0.26	-0.14	-0.22	0.11	0.07	0.08
SEM	3.20	8.29	4.33	4.99	9.72	5.31
MDC90	7.43	19.29	10.07	11.62	22.61	12.35
Percent changing MDC <sub>90</sub>	12.23	11.94	12.78	29.45	9.17	31.95

 $ES = effect size = (M_2-M_1)/S_b$ , where  $M_2$  is the mean score at year 2,  $M_1$  is the mean score at baseline, and  $S_b$  is the standard deviation at baseline; SRH = self-rated health; SPPB = Short Physical Performance Battery; SEM = standard error of measurement =  $S_b^*$  (1-r), where  $S_b$  is the standard deviation at baseline and r is the test-retest reliability coefficient;  $MDC_{90} = minimal$  detectable change with 90% confidence =  $SEM^*1.645^*sqrt2$ .

n=360 except where otherwise indicated