Published in final edited form as:

PM R. 2014 November ; 6(11): 976–987. doi:10.1016/j.pmrj.2014.05.001.

Establishing an Approach to Activity of Daily Living and Instrumental Activity of Daily Living Staging in the United States Adult Community-Dwelling Medicare Population

Margaret G. Stineman, MD,

Department of Biostatistics and Epidemiology, The Center for Clinical Epidemiology and Biostatistics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA; Department of Physical Medicine and Rehabilitation, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA

Joel E. Streim, MD,

Geriatric Psychiatry Section of the Department of Psychiatry, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, and VISN

Qiang Pan, MA,

Department of Biostatistics and Epidemiology, The Center for Clinical Epidemiology and Biostatistics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA

Jibby E. Kurichi, MPH,

Department of Biostatistics and Epidemiology, The Center for Clinical Epidemiology and Biostatistics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA; 423 Guardian Drive, 907 Blockley Hall, Philadelphia, PA 19104-6021

Sophia Miryam Schüssler-Fiorenza Rose, MD, PhD, and

Mental Illness Research Education & Clinical Center, Philadelphia Veterans Affairs Medical Center, Philadelphia, PA; and VA Healthcare System Palo Alto, Spinal Cord Injury Service

Dawei Xie, PhD

Department of Biostatistics and Epidemiology, Center for Clinical Epidemiology and Biostatistics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA

Abstract

Background—Stages quantify severity like conventional measures but further specify the activities that people are still able to perform without difficulty.

Objective—To develop Activity Limitation Stages for defining and monitoring groups of adult community-dwelling Medicare beneficiaries.

Design—Cross-sectional.

Setting—Community.

Participants—There were 14,670 respondents to the 2006 Medicare Current Beneficiary Survey.

Methods—Stages were empirically derived for the Activities of Daily Living (ADLs) and the Instrumental Activities of Daily Living (IADLs) by profiling the distribution of performance difficulties as reported by beneficiaries or their proxies. Stage prevalence estimates were determined, and associations with demographic and health variables were examined for all community-dwelling Medicare beneficiaries.

Main outcome measures—ADL and IADL stage prevalence.

Results—Stages (0-IV) define 5 groups across the separate ADL and IADL domains according to hierarchically organized profiles of retained abilities and difficulties. For example, at ADL-I, people are guaranteed to be able to eat, toilet, dress, and bathe/shower without difficulty, whereas they experience limitations getting in and out of bed or chairs and difficulties walking. In 2006, an estimated 6.0, 2.9, 2.2, and 0.5 million beneficiaries had mild (ADL-I), moderate (ADL-II), severe (ADL-III), and complete (ADL-IV) difficulties, respectively, with estimates for IADL stages even higher. ADL and IADL stages showed expected associations with age and health-related concepts, supporting construct validity. Stages showed the strongest associations with conditions that impair cognition.

Conclusions—Stages as aggregate measures reveal the ADLs and IADLs that people are still able to do without difficulty, along with those activities in which they report having difficulty, consequently emphasizing how groups of people with difficulties can still participate in their own lives. Over the coming decades, stages applied to populations served by vertically integrated clinical practices could facilitate large-scale planning, with the goal of maximizing personal autonomy among groups of community-dwelling people with disabilities.

INTRODUCTION

It is argued by some that, as an organizing principle for US health care, approaching each patient strictly as an individual is obsolete, and that the population health approach is an alternative for improving and maintaining the health of everyone in the community [1]. If this approach becomes widely adopted, then rehabilitation medicine, the medical field dedicated to the well-being of persons with disabilities, will need meaningful population-level measures of activity limitation as it seeks to promote the health and function of defined populations of persons with disabilities.

Recognizing the need to address the magnitude of disability in the US population, in its 2007 report, “Future of Disability in America” [2], the Institute of Medicine called for the creation of comprehensive disability monitoring systems applying International Classification of Functioning, Disability and Health (ICF) terminology and concepts [3]. Consequently, we derived a disability staging system based on the ICF concepts [4] of activity and participation. Within the ICF, activity constitutes the “execution of a task by an individual,” and participation represents “involvement in a life situation,” characterized according to identical sets of “chapters” [3]. Stages describe patterns of activity limitation across the classical Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), each of which includes 6 tasks[3,5,6] corresponding closely to the ICF

chapters of self-care and domestic life, respectively. ADLs, everyday tasks necessary for self-care, were rated by consumers as the most important set of items among activities included in a large item bank [7]. IADLs, more complex domestic life and household management tasks, are necessary for all individuals if they are to participate in community life.

ADL and IADL stages were designed to reflect standard ICF performance qualifiers. Stage 0 represents “no”; stage I, “mild”; stage II, “moderate”; stage III, “severe”; and stage IV, “complete” activity limitation within the domain measured. People at stage 0 are able to execute all 6 activities without difficulty. People at stages I and II have progressively fewer tasks they are guaranteed able to perform without difficulty, beginning with the typically harder and ending with those that are easier. People at stage IV experience difficulties in all 6 ADLs or IADLs. Recognizing that individuals’ activity limitations will not always follow typical hierarchies, stage III is reserved for people with unusual patterns of limitations reporting typically easy activity/activities as difficult, and 1 or more easier activities as not difficult. Higher numbered stages reflect more severe disabilities, but also qualitatively different limitations.

ADL and IADL stages differ from typical population-level measures of ADLs and IADLs. Population-level measures commonly express severity by counting the activities that are limited or by producing scores that compile individuals’ status across multiple activities [8,9]. Counts and scores do not specify which activities are limited. This means that people with very different patterns of ADL or IADL limitations can have the same counts or scores. In contrast, stage thresholds are hierarchical, reflecting the most common patterns of functional recovery and loss according to long-recognized ADL and IADL hierarchies [5,6]. At mild stages of limitation, people are able to execute all but the typically “hardest” activities without difficulty, that is, those activities reported most frequently as being difficult by individuals in the target population for which stages were derived. At more severe stages, even the “easiest” activities, that is, those least frequently reported as difficult, become limited.

To test the concept, ADL and IADL stages were initially derived from the Second Longitudinal Study of Aging (LSOA II) because these legacy data contained an exceptionally rich set of person- and environmental-level variables appropriate to testing construct and predictive validity. Higher stages of ADL and/or IADL limitation were associated with logical patterns of comorbidities, perceptions of unmet need for home environmental modifications, history of multiple falls, difficulties inside the home, difficulties entering or leaving the home, urinary and fecal incontinence, hospitalization in the previous month, greater risks of nursing home placement within a 2-year period, and higher 1-, 5-, and 10-year mortality [10-15]. Perceived unmet needs for home accessibility features, advanced age, and the presence of conditions expected to be progressively disabling, such as arthritis, predicted decline to higher stages of limitation over 2 years [16].

The LSOA II data were representative of the elderly US population of community-dwelling adults 70 years of age or older in 1994-1995. Because the LSOA II survey is no longer collected, future usefulness of these ADL and IADL stages is limited. Consequently, in this

study, we first rederived ADL and IADL stages by applying data from the Medicare Current Beneficiary Survey (MCBS). Because the MCBS is a continuous and ongoing panel survey that is applied in policy determination, ADL and IADL stages derived in these data will enable surveillance of the entire contemporary US community-dwelling adult Medicare population [17] and might offer a means for health care systems to address, with greater precision, the community-support needs of distinct subpopulations for which they are providing care.

Second, we determined the degree to which stage thresholds re-defined in the MCBS data are similar to or differ from those derived in the LSOA II. We anticipate possible differences because the original definitions reflected responses from individuals almost 2 decades ago, were limited to those who were 70 years of age and older, and may not generalize to younger Medicare beneficiaries or to cohorts living in more recent times.

Third, we examined cross-sectional associations between the MCBS-based ADL and IADL stages and variables in the MCBS data that were previously shown to correlate with ADL and IADL stages in the LSOA II data. We hypothesized that people at higher stages of ADL and IADL limitation would be more likely to have histories of previous strokes and diagnoses of Alzheimer's disease or dementia. According to our previous findings [4], we further anticipated that people with medical conditions less often associated with intellectual impairment would tend to cluster at the intermediate stages of difficulty. Finally, we anticipated strong correlations between perceptions of poorer health and higher stages of ADL and IADL limitation.

METHODS

The current analysis was approved by the institutional review board at the University of Pennsylvania.

Data Source and Study Population

Data were from the MCBS 2006 Access to Care files representative of continuously enrolled persons in Medicare. To be representative of the Medicare population as a whole, the MCBS draws its sample from the Medicare enrollment file[17,18]. To address their special health care needs, those individuals 64 years of age and under as well as those 85 years and older are oversampled. We included all community-dwelling beneficiaries with 2006 MCBS Access to Care interviews. The 2006 MCBS Access to Care sample includes 4 independent panels, of which each independent panel entered the survey in different years (N = 14,732), all of whom were interviewed in 2006. The cumulative response rates were 63.9%, 66.3%, 69.5%, and 82.8% for the 4 panels entering in 2003, 2004, 2005, and 2006, respectively [17]. Survey weights adjust for nonresponse [19]. Among all community-dwelling participants, 62 participants were excluded because they had some variables missing, leaving 14,670 beneficiaries for analysis.

Answers provided by these respondents to questions in the 2006 MCBS Access to Care Health Status and Functioning Questionnaire about difficulties experienced when performing activities were used to generate the ADL and IADL stages. Table 1 compares the

exact wording as defined for the MCBS for the introductory instructions, lead in, and questions about each activity (ADL and IADL) to those in the LSOA II. Questions about difficulty in both surveys were asked about 6 ADLs including eating, toileting, dressing, bathing/showering, getting in/out of bed/chairs, and walking; and 6 IADLs including using the telephone, managing money, preparing one's own meals, light housework, shopping for personal items, and heavy housework. Each included a dichotomous response regarding performance difficulty (yes or no). The classification of this set of MCBS items into ADL and IADLs is consistent with previous work [20]. Sometimes persons responding to the MCBS questions stated that they did not do IADLs. If the reason for not performing an IADL was reported to be health related, the activity was counted as being "Difficult." If the reason was reported as not health related, the IADL was counted as "Not difficult." Otherwise, the IADL was counted as "Missing." For the purpose of this analysis, those individuals who received help for an activity were counted as experiencing difficulty" [19]. Sociodemographics included age (<65, 65-80, and >80 years), sex (male as reference), and race (non-Hispanic white [as reference], non-Hispanic black or African American, Hispanic, and other). The age categories were selected to be consistent with Centers for Medicare & Medicaid Services (CMS) data reporting structure, with groups combined because of small sample sizes.

Medical Conditions and Illness Categories

Both the MCBS and the LSOA II asked respondents whether a doctor had ever told the sample person (SP) that he or she had any of several common chronic health conditions. We created simplified health conditions and illness categories in the MCBS to maximally replicate those in the LSOA II. Stroke, brain hemorrhage, cerebrovascular accident, and paralysis were combined in the illness category "stroke." A history of Alzheimer's disease or dementia was combined into a "dementia" category. Depression and other psychiatric conditions were placed into a "psychiatric" category. "Osteoporosis" was used for the conditions that asked about brittle or fragile bones. Type 1 and type 2, that is, insulin-dependent and non-insulin-dependent, diabetes mellitus were combined as "diabetes." Myocardial infarction, angina pectoris, congestive heart failure, valve disorders, rhythm disturbances, other heart conditions, emphysema, and chronic obstructive pulmonary disease (COPD) were included in a "cardiopulmonary" category. Rheumatoid and any other types of arthritis were combined into an "arthritis" category. All types of cancers were combined in a single "cancer" category, excluding skin, as only a small proportion will likely be disabling. The condition "hypertension" was anticipated to have the least association with stage of all conditions and categories.

Perceived health was addressed by asking the respondent to rate the SP's health as excellent, very good, good, fair, or poor as separate categories compared to that of people of the same age.

Analysis

The 5 stages were derived for ADL and IADL separately as described previously [4,21-23], applying patient or close proxy responses to questions in the MCBS Access to Care questionnaire. Similar to Item Response Theory-based measures, the derivation of stages

relies on underlying item difficulty hierarchies [24] as uncovered through the analyses of item response prevalence, where 0 = not difficult and 1 = difficult. The item responses within the stages are ordered by the probability that individuals with mild, moderate, severe, and complete limitations (as defined from counts of activity limitations) would describe difficulty performing each activity. Among item responses within the ADL and IADL domains, the tasks with the highest prevalence of difficulty were considered most difficult in the hierarchy and the tasks with the lowest prevalence of difficulty the easiest. Consequently, stage thresholds, based on the prevalence of reported difficulty with ADL and IADL items, reflect the most common patterns of activity limitation in the Medicare beneficiary sample, with those individuals whose limitations fall outside the typical hierarchy classified in the nonfitting stages (III). Comparison of MCBS stages with LSOA II stages was based on addressing the degree to which the stage thresholds changed. Unadjusted associations between sociodemographics, health conditions, and the presence (combines stages I, II, III, and IV for easy presentation) versus absence (stage 0) of ADL and IADL limitation were determined.

To determine adjusted associations between stages and each chronic health condition and perceived health status, models were fitted adjusting for demographics because of known associations of age, sex, and race/ethnicity with functioning and other health constructs [25]. Because stages have multiple levels, multinomial logistic regression models were fitted on the ADL and IADL stages as follows: model 1, comprising age, sex, race/ethnicity, and presence of chronic conditions; and model 2, comprising age, sex, race, and perceived health status. Models 1 and 2 were fitted separately because of intercorrelation between the presence of chronic health conditions and perceived health status.

All statistical analyses were performed with SAS version 9.3 (SAS Institute, Cary, NC), using the proper statements to account for complex sampling including weight, clustering, stratification, and subpopulation [26]. For the 2 models above, proc surveylogistic was applied to model the ratio of the probability of being at another stage (ie, stage I) to the probability of being at the reference stage (ie, stage 0). Assuming only 2 levels (ie, stages 0 and I) in the outcome, the ratio modeled would have been the odds of being at stage I. With multiple stages, the ratio becomes the relative risk (RR) of being at stage I, II, III, or IV relative to stage 0. Relative risk ratios are similar to odds ratios in logistic regression models. Their 95% confidence intervals were reported. All *p* values presented are 2-tailed; *p* values less than .05 were considered statistically significant.

RESULTS

All proportions are presented as weighted percentages unless otherwise stated. The vast majority of respondents (91.0%) reported information for themselves. Of the 9% for whom a proxy was used, 26.6% were seen as not capable mentally (poor memory or psychiatric problems), 21.8% not capable physically (illness, blindness, or inability to speak), 11.0% were deemed not capable both mentally and physically, and the remaining 40.7% used a proxy respondent for 1 or more other reasons (inability to provide information regarding medical records, language problems, being in the hospital, preferring proxy to answer,

information not available, or other). Slightly more than half (53.7%) were married, and 16.6% of the beneficiaries were dually eligible for Medicare and Medicaid.

The ADL and IADL stage threshold definitions as defined for the MCBS are shown in Table 2. For a person to be at an ADL or IADL stage, the italicized statement must be true. Individuals can be staged based on answers to the MCBS questions in Table 1. They may or may not have difficulty with the nonitalicized activities. For example, a woman who states that she has difficulty walking, getting in or out of bed and chairs, shopping, and doing heavy housework tasks because of arthritis but can do all of the other tasks without difficulty is at ADL-I and IADL-I. For another example, a spouse answering for her husband who states that he is no longer able to manage money or use a telephone but is still able to do some of the other IADL items without difficulty is at IADL-III.

By examining the range of prevalence rates of reported difficulty for each ADL item, we determined which ADLs are most commonly experienced within the survey population as difficult or easy to perform. As described in the preceding section, Derivation of Stages, the most commonly difficult items were used to establish stage thresholds. To be classified at stage 0, one cannot experience difficulty with any ADL or IADL item. ADL stage I is defined by difficulty getting in or out of bed/chair and/or walking; IADL stage I is defined by difficulty shopping and/or doing heavy housework, because those were the items for which the prevalence of reported difficulty was greatest within the MCBS sample. To be classified at ADL stage II, an individual is guaranteed not to have difficulty with eating or toileting, but may have difficulty with the remaining ADL items that were associated with the highest prevalence of difficulty reported in the MCBS sample. Similarly, to be classified at IADL stage II, an individual is guaranteed not to have difficulty using the telephone or managing money, but may have difficulty with the remaining IADL items that were associated with the highest prevalence of reported difficulty. For a person to be at ADL stage III, the individual may have difficulty with eating and/or toileting but not with all of the ADLs. To be at IADL stage III, the person may have difficulty using the telephone and/or managing money but not with all of the IADLs. At stage IV, all ADLs and IADLs are difficult.

With regard to the hierarchy across the ADL stage thresholds, compared to our earlier stages, in the MCBS ADL stages, eating and toileting remained the easiest (defined by being the least commonly difficult activities in the population). Dressing remained among 1 of the 2 items of intermediate difficulty. Walking continued to be in the most difficult category (ie, being among the items most commonly endorsed as difficult). Getting in/out of bed/chairs in the intermediate difficulty category in the LSOA II stages moved to the most difficult category in the MCBS stages, and bathing/showering moved from the most difficult into the intermediate category. There were no differences in the IADL stage hierarchy.

Table 3 displays the estimated population size and prevalence by stage in the 2006 community-dwelling Medicare population. IADL limitations were slightly more prevalent than ADL limitations, and the numbers and prevalence of beneficiaries declined sharply as stage of activity limitation increased. For example, only 1.3% and 2.3% of the community-

dwelling Medicare population can be expected to be at the highest stages of ADL and IADL difficulty, respectively.

Table 4 shows the unadjusted associations between the presence and absence of ADL and IADL limitations, sociodemographic variables, presence of specific chronic conditions, and perceived health status. There were 15.5% of beneficiaries younger than 65 years, 60.4% from 65 to 80 years, and 24.1% 80 years or older. An estimated 55.2% and 83.8% of beneficiaries were female and non-Hispanic white, respectively. The most common health conditions were arthritis and hypertension, with estimated population prevalences of 58.3% and 62.8%, respectively.

Those with ADL and IADL limitation are most likely in the younger or oldest groups than in the 65- to 80-year age group. The unadjusted prevalence of nearly all individual health conditions was higher for those individuals with compared to those without ADL conditions and for those with and without IADL conditions. Individuals with poor perceived health tended to be at the higher stages of limitation.

Dementia and stroke were the conditions most strongly ordered and associated with stage after adjusting for all other conditions as well as demographics as shown in Figure 1 a and b (model 1). The relative risk ratios for ADL stages I, II, III, and IV compared to 0, comparing those individuals with to those without dementia, were 1.30, 2.73, 3.57, and 14.87, respectively. Comparing those individuals with a history of stroke to those without a history of stroke, relative risk ratios for ADL stages I, II, III, and IV with stage 0 as reference were 1.84, 2.52, 2.95, and 6.09. There were some differences between the ADL and IADL stage associations. The psychiatric category had an ordered association with IADL stages but was less ordered for ADL stages. For medical conditions such as diabetes, the relative risk ratios tended to be higher comparing ADL-I, and II to 0, attenuating at ADL-III, and often became insignificant comparing stage IV to 0. The medical condition patterns were similar for IADL stages.

After reducing the effects of demographics (Figure 2 a and b), there were strong and ordered associations between perception of poorer health and being at a more limited ADL stage (model 2). For example, the RR of being at ADL-I for a patient with perceptions of very good health was 2.27 times the RR for a person with excellent health. For ADLs, relative risk ratios increased from 2.27 to 4.39 to 8.81 to 13.68 for those individuals whose health was perceived as good, fair, and poor, respectively. Looking across stages, the relative risk ratios for perception of health showed a strong and ordered increase as stage of limitation became greater for ADLs but less so for IADLs particularly for fair and poor health. The associations had some similarities across the 2 domains for stages I, II, and IV compared to 0 but diverged for stage III. IADL-III appeared to be out of order.

DISCUSSION

ADL and IADL stages were re-derived in the contemporary MCBS applying the ICF-based structure [11]. Stages derived in these data can enable surveillance of the community-dwelling adult Medicare population [17], thus helping to prepare the rehabilitation work

force and the larger US health care system to meet the specific community-supportive needs of groups of persons with distinct activity limitations. As aggregate measures of disability, ADL and IADL stages are unique because they specify the self-care and domestic life tasks that groups of individuals with disabilities are still able to participate in without difficulty, drawing attention to autonomy and the potential for self-direction, while still expressing the magnitude and nature of the tasks that these individuals have difficulty performing. As global measures, ADL and IADL stages can facilitate comparisons of the consequences of different conditions and life circumstances on activity limitation or participation. As health care systems accept risk for providing health care to defined panels or populations of patients, we anticipate that stages may serve as a tool to use both individual- and population-level approaches to measuring disability, need for resources, and changes in activity limitation (trajectories of decline or recovery of function).

ADL Comparison

The empirically derived sequences of activity difficulties across MCBS-based ADL stages were similar but not identical to LSOA II-based stages deviating slightly from the classical hierarchical ordering of activities as originally defined 5 decades ago [5]. Consistent with more recent item response theory-based analyses [27], the MCBS-based ADL stages presented here suggest shifts in the item difficulty hierarchy such that bathing/showering became relatively easier than transferring. There are several possible explanations. Increased health care provider recognition of need for and continued Medicare coverage of durable medical equipment, coupled with improved architectural design as stimulated by the Americans with Disabilities Act [28], may be encouraging shifts. Recent population-level findings document higher proportions of people in the US population using equipment for limitations in bathing [29]. Consequently, the relative ease of bathing/showering in the latter MCBS sample may reflect diffusion of shower stalls and increasing use of transfer boards, stools, and accessibility features in homes. Alternatively, even minor changes in the wording of questions about activities can change the threshold at which people will recognize difficulties, and thus the hierarchical ordering of items [30-32].

IADL Comparison

In contrast to ADLs, the ordering of activities across the IADL stage thresholds within the MCBS-derived stages remained identical to that established in the LSOA II stages, reflecting no change from the classical hierarchy [6]. Yet, the apparent shift in relative difficulties among ADLs highlights the importance of periodically re-deriving stages and other functional measures that reflect hierarchies. It is essential to recognize that the physical and social living environments are not static, and that environmental changes in the population [33] could be associated with the evolution of self-reported abilities and disabilities.

Construct Validity

Concordance with LSOA II-based stages [4,34], previous studies [25,35,36], clinical plausibility, and associations between MCBS-based ADL and IADL stages support their construct validity. In general, patterns of association between ADL and IADL stages in the adult Medicare population in 2006 MCBS data across different type(s) of mental and

physical disorders were similar to those obtained in 1994 and 1995, according to our LSOA II-based ADL and IADL stages. Because the age structures of the LSOA II and the MCBS differ, associations with age cannot be readily compared across the 2 staging systems.

In both data sets, cognitive impairment appears to be important, as can be seen in central nervous system conditions such as dementia and stroke. Dementia, by definition, impairs cognition, and consistently showed the highest and most ordered association with both ADL and IADL stage across both data sources. Stroke can include motor, cognitive impairment, or both, and it is likely that both contribute to the strong, consistent ordered pattern with increasing stage of limitation. In the MCBS, the category of “psychiatric,” which included depression and other psychiatric conditions, showed an ordered association similar to the central nervous system conditions; however, this was less apparent with the corresponding LSOA II category “major psychiatric disorders.”

In contrast to central nervous system conditions, in both data sets, other medical condition categories such as cardiopulmonary, diabetes, and arthritis were associated with an increased likelihood of activity limitation, which attenuated at stages III and IV, suggesting that these conditions typically generate mild or moderate, rather than severe, limitations. Although these conditions appear more often to be associated with milder activity limitation, their high prevalence raises their importance. Cancer as a broad category showed little association in either of the data sets, which we attributed to the heterogeneity of organ involvement. Logically, as shown previously in the LSOA II data, the presence of hypertension, generally asymptomatic, had little association with stage.

The strong association shown of health perceptions with ADL stage such that those individuals with greater difficulties consistently rated themselves or were rated by proxies as being in poorer health, was consistent with LSOA II-based stages. IADL-III in the MCBS may be hierarchically out of order because it represents the point in disability trajectory when tasks such as telephoning and money management become difficult, likely heralding the onset of significant intellectual impairment.

Significance of Stages

Intended to optimize and to encourage participation and autonomy among people living in the community who have disabilities, stages are structured to emphasize what people are still able to do without difficulty. Consequently, stages, compared to other types of population measures, advance disability surveillance by generating clinically interpretable profiles of abilities and disabilities that describe preserved abilities and more explicitly address elements of activity limitation while still retaining properties of an aggregate measure. The distinctions between ADL and IADL stages and other measures are most easily seen when comparing stages to simple count strata.

Clearly, persons with 3 or 4, compared to those with 1 or 2, difficulties have more severe disabilities, but the specific tasks that they are still able to do without difficulty are not specified by the count. Similarly, people at stage II compared to those at stage I have more severe disabilities, and, in sharp contrast to counts, we know for certain the tasks that they are still able to do without difficulty. Consequently, stages provide a more powerful lens

than counts, and, by focusing on how people are able to participate in self-care and domestic life tasks, have major implications for future health care planning. For example, there were almost 3 million adult Medicare beneficiaries estimated to be at ADL-II in 2006 (Table 3). Persons in this group are guaranteed to be able to eat and to use the toilet without difficulty. For those who are functionally stable over time, caregivers working with them will not need to address these tasks. All will have difficulties in some combination of the other ADLs, that is, dressing, bathing, transferring, and walking, and may need help in these areas. For another example, the approximately 6.5 million beneficiaries at IADL-I were guaranteed to be able to use a telephone, manage their own money, cook, and do light housework without difficulty. However, all of them will have difficulty with shopping and/or heavy housework tasks. Consequently, grouping populations of people by ADL and IADL stage provides a way to identify subpopulations tending to require similar types of supportive services, assistive technologies, or other approaches to support their remaining in the community.

The choice to use Activity Limitation Stages as opposed to other aggregated approaches to measurement of activity limitation will depend on the application. Counts provide the simplest and most easily derived estimates of severity, whereas item response theory-based measures allow the most precise estimates and, through a computer interface, make it possible to select questions tailored to patients' functional abilities [37]. Stages yield both a severity estimate and disability profile, and therefore will have utility for a wide array of lay and professional stakeholders when it is essential to know the implications of disability. The crude distributions of beneficiaries according to ADL and IADL stages, unlike counts, can help to project the magnitude of population-level health and supportive needs across the broader ADL and IADL domains. Stages improve on the information captured by counts by providing more explicit information about the status of individual activities and thus the qualitative nature of disabilities.

Study Limitations

This work has a number of limitations. First, it was intended to focus exclusively on community-dwelling Medicare beneficiaries, recognizing that those residing in long-term care facilities represent a different population. Moreover, as a patient-reported measure, if certain groups differ in their perception of what constitutes difficulty performing an activity or a level of subjective health, these differences could bias findings [38,39]. This concern is not unique to staging, as it will be present for any patient- or self-reported ratings of health status, functional status, or outcomes that depend on the perception of individuals (or those close to them) about their lives. Although we recognize potential subpopulation differences, our stage definitions were intended to be global as a way to characterize broad adult subpopulations needing similar types of supports to participate in community life.

Also, we included information from proxy respondents. As proxies may not respond to questions about a person in the same way that that person would respond, the inclusion of proxy information could bias questions that relate to self-perception. We chose to include proxy information because a small minority used proxy respondents (<10%) and because previous findings suggest that the exclusion of persons for whom proxies report could introduce bias [40]. Moderate to strong participant-proxy agreement across a variety of

disability-related questions among persons with different types of impairments supported the inclusion of proxy data [41]. Such exclusion would eliminate from consideration some of the most disabled and vulnerable individuals in the population, especially those with conditions that impair cognitive function, potentially disenfranchising those with dementia.

Finally, there is evidence that disability rates determined by survey may underestimate prevalence when compared to rates derived through clinical assessment [42]. Recognizing that clinical assessments of activity limitation may not be practical for population surveillance on a wide scale, policy makers need to be cognizant of potential estimation bias from survey data about activity limitations.

There are alternative ways to ask about activity limitations. The 2 primary questions relate to difficulty experienced and help received. We chose difficulty rather than help because we were concerned about how people who need help but who do not have help available might respond to such a question. These individuals may be among the most vulnerable. Future work might include more broadly constructed definitions of disability that combine ADLs and IADLs in a single system [43]. Future studies will be essential in recognizing the special characteristics and needs of different subpopulations by stage.

CONCLUSIONS

Future work will need to elucidate interventions to maintain and to improve independence for individuals at various stages within the adult, community-dwelling Medicare population. In the meantime, we hope that use of ADL and IADL stages can serve as a tool for a broad array of stakeholders, policymakers, payers, clinicians, researchers, health care delivery systems, and consumers to make better-informed, cost-efficient decisions that maximize the health, functioning, and quality of life of Medicare populations.

Acknowledgments

The research for this manuscript was supported by grants from the National Institute of Aging of the National Institutes of Health (AG032420-01A1 and R01 AG 040105-01A1).

We certify that no party having a direct interest in the results of the research supporting this article has or will confer a benefit on us or on any organization with which we are associated AND, if applicable, we certify that all financial and material support for this research (i.e., National Institutes of Health grants) and work are clearly identified in the title page of the manuscript. The opinions and conclusions of the authors are not necessarily those of the sponsoring agencies. Parts of the material were presented at an AAPM&R Annual Assembly as Stineman MG, Schüssler-Fiorenza M, Qiang P, Streim J, Kurichi JE, Xie D. Understanding the Severity and Types of Activity Limitation in Large Populations through Disability Staging presented at American Academy of Physical Medicine and Rehabilitation 75th Annual Assembly, National Harbor, Maryland, October 3-6, 2013. No medical devices are described in the study.

REFERENCES

1. Sox HC. Resolving the tension between population health and individual health care. *JAMA*. 2013; 310:1933–1934. [PubMed: 24219944]
2. Committee on Disability in America. *The Future of Disability in America*. 1 ed.. Field, MJ.; Jette, A., editors. National Academies Press; Washington, DC: 2007. p. 618
3. World Health Organization. *International Classification of Functioning, Disability and Health: ICF*. World Health Organization; Geneva, Switzerland: 2001.

4. Stineman MG, Henry-Sanchez JT, Kurichi JE, et al. Staging activity limitation and participation restriction in elderly community-dwelling persons according to difficulties in self-care and domestic life functioning. *Am J Phys Med Rehabil.* 2012; 91:126–140. [PubMed: 22248806]
5. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged. The Index of ADL: A standardized measure of biological and psychosocial function. *JAMA.* 1963; 185:914–919. [PubMed: 14044222]
6. Lawton MP, Brody EM. Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist.* 1969; 9:179–186. [PubMed: 5349366]
7. Bruce B, Fries JF, Ambrosini D, et al. Better assessment of physical function: Item improvement is neglected but essential. *Arthritis Res Ther.* 2009; 11:R191. [PubMed: 20015354]
8. [Agingstats.gov](http://agingstats.gov). Federal Interagency Forum on Aging Related Statistics. [Accessed January 20, 2013] Older Americans 2008: Key indicators of well-being 2008. [Agingstats.gov Available at http://www.agingstats.gov/agingstatsdotnet/Main_Site/Data/2008_Documents/Health_Status.pdf](http://www.agingstats.gov/agingstatsdotnet/Main_Site/Data/2008_Documents/Health_Status.pdf)
9. Kautter JPG. CMS Frailty Adjustment Model. *Health Care Financ Rev.* 2004-2005; 26:1–19. [PubMed: 25372243]
10. Henry-Sanchez JT, Kurichi JE, Xie D, Pan Q, Stineman MG. Do elderly people at more severe activity of daily living limitation stages fall more? *Am J Phys Med Rehabil.* 2012; 91:601–610. [PubMed: 22561383]
11. Stineman MG, Xie D, Streim JE, et al. Home accessibility, living circumstances, stage of activity limitation, and nursing home use. *Arch Phys Med Rehabil.* 2012
12. Stineman MG, Ross RN, Maislin G, Gray D. Population-based study of home accessibility features and the activities of daily living: Clinical and policy implications. *Disabil Rehabil.* 2007; 29:1165–1175. [PubMed: 17653990]
13. Zhang Z, Xie DW, Kurichi JE, Streim J, Zhang GY, Stineman MG. Mortality predictive indexes for the community-dwelling elderly US population. *J Gen Intern Med.* 2012; 27:901–910. [PubMed: 22422075]
14. Brown J, Kurichi JE, Xie D, Pan Q, Stineman MG. Instrumental activities of daily living staging as a possible clinical tool for falls risk assessment in PM&R. *PM R.* 2013
15. Schussler-Fioreza CM, Xie D, Pan Q, Stineman MG. Comparison of complex versus simple activity of daily living staging: Validation of simple stages. *Arch Phys Med Rehabil.* 2013; 94:1320–1327. [PubMed: 23313353]
16. Stineman MG, Zhang G, Kurichi JE, et al. Prognosis for functional deterioration and functional improvement in late life among community-dwelling persons. *PM R.* 2013; 5:360–371. [PubMed: 23454447]
17. Centers for Medicare & Medicaid Services. [Accessed February 21, 2013] Medicare Current Beneficiary Survey (MCBS) access to care introduction 2006. Available at <https://www.cms.gov/MCBS/>
18. US Department of Health & Human Services. [Accessed February 20, 2013] Medicare Current Beneficiary Survey (MCBS) 2010. Available at <http://www.cms.hhs.gov/MCBS/>
19. Center for Medicare and Medicaid Services. [Accessed November 28, 2013] Medicare Current Beneficiary Survey CY 2006 Cost and Use Survey Section 3 Health Status and function p 9, 2009. Feb 22. 2012 Available at <https://www.cms.gov/MCBS/>
20. Waidmann TA, Liu K. Disability trends among elderly persons and implications for the future. *J Gerontol B Psychol Sci Soc Sci.* 2000; 55:S298–S307. [PubMed: 10985301]
21. Stineman MG, Ross RN, Fiedler R, Granger CV, Maislin G. Staging functional independence validity and applications. *Arch Phys Med Rehabil.* 2003; 84:38–45. [PubMed: 12589618]
22. Stineman MG, Ross RN, Fiedler R, Granger CV, Maislin G. Functional independence staging: Conceptual foundation, face validity, and empirical derivation. *Arch Phys Med Rehabil.* 2003; 84:29–37. [PubMed: 12589617]
23. Stineman MG, Ross RN, Granger CV, Maislin G. Predicting the achievement of 6 grades of physical independence from data routinely collected at admission to rehabilitation. *Arch Phys Med Rehabil.* 2003; 84:1647–1656. [PubMed: 14639565]

24. Carle AC, Cella D, Cai L, et al. Advancing PROMIS's methodology: Results of the Third Patient-Reported Outcomes Measurement Information System (PROMIS((R))) Psychometric Summit. *Expert Rev Pharmacoecon Outcomes Res.* 2011; 11:677–684. [PubMed: 22098283]
25. Boyington JE, Howard DL, Holmes DN. Self-rated health, activities of daily living, and mobility limitations among black and white stroke survivors. *J Aging Health.* 2008; 20:920–939. [PubMed: 18836032]
26. Lo A, Ghu A. Variance estimation and the components of variance for the Medicare Current Beneficiary Survey sample. *Am Stat Assoc Sect Surv Res Methods.* 2005:3333–3341.
27. Saliba D, Orlando M, Wenger NS, Hays RD, Rubenstein LZ. Identifying a short functional disability screen for older persons. *J Gerontol A Biol Sci Med Sci.* 2000; 55:M750–M756. [PubMed: 11129398]
28. US Department of Justice. [Accessed January 1, 2013] ADA Home Page: Information and technical assistance on the Americans with Disabilities Act 2011. Available at <http://www.ada.gov/>
29. Spillman BC. Changes in elderly disability rates and the implications for health care utilization and cost. *Milbank Q.* 2004; 82:157–194. [PubMed: 15016247]
30. Kempen GI, Myers AM, Powell LE. Hierarchical structure in ADL and IADL: Analytical assumptions and applications for clinicians and researchers. *J Clin Epidemiol.* 1995; 48:1299–1305. [PubMed: 7490592]
31. Picavet HS, van den Bos GA. Comparing survey data on functional disability: The impact of some methodological differences. *J Epidemiol Community Health.* 1996; 50:86–93. [PubMed: 8762361]
32. Wiener JM, Hanley RJ, Clark R, Van Nostrand JF. Measuring the activities of daily living: Comparisons across national surveys. *J Gerontol.* 1990; 45:S229–S237. [PubMed: 2146312]
33. Stineman MG, Streim JE. The biopsychological paradigm: A foundational theory for medicine. *PM R.* 2010; 2:1035–1045. [PubMed: 21093839]
34. Stineman MG, Xie D, Pan Q, Kurichi JE, Saliba D, Streim J. Activity of daily living staging, chronic health conditions, and perceived lack of home accessibility features for elderly people living in the community. *J Am Geriatr Soc.* 2011; 59:454–462. [PubMed: 21361881]
35. Herman DR, Solomons NW, Mendoza I, Qureshi AK. Self-rated health and its relationship to functional status and well-being in a group of elderly Guatemalan subjects. *Asia Pac J Clin Nutr.* 2001; 10:176–182.
36. Lee Y. The predictive value of self assessed general, physical, and mental health on functional decline and mortality in older adults. *J Epidemiol Community Health.* 2000; 54:123–129. [PubMed: 10715745]
37. Jette AM, Keysor JJ. Assessing the field of disability research 3. Uses of evidence in disability outcomes and effectiveness research. *Milbank Q.* 2002; 80:325–345. [PubMed: 12101875]
38. Stewart ST, Woodward RM, Rosen AB, Cutler DM. The impact of symptoms and impairments on overall health in US national health data. *Med Care.* 2008; 46:954–962. [PubMed: 18725850]
39. Kaplan G, Baron-Epel O. What lies behind the subjective evaluation of health status? *Soc Sci Med.* 2003; 56:1669–1676. [PubMed: 12639584]
40. Stineman MG, Ross RN, Maislin G. Functional status measures for integrating medical and social care. *Int J Integr Care.* 2005; 5:e07. [PubMed: 16773164]
41. Cusick CP, Brooks CA, Whiteneck GG. The use of proxies in community integration research. *Arch Phys Med Rehabil.* 2001; 82:1018–1024. [PubMed: 11494179]
42. Walsh EG, Khatutsky G. Mode of administration effects on disability measures in a sample of frail beneficiaries. *Gerontologist.* 2007; 47:838–844. [PubMed: 18192637]
43. Altman BM, Cooper PF, Cunningham PJ. The case of disability in the family: Impact on health care utilization and expenditures for nondisabled members. *Milbank Q.* 1999; 77:39–75. iv. [PubMed: 10197027]

Figure 1.

(a) Activities of Daily Living (ADL) stage patterns of association between different types of mental and physical conditions. (b) Instrumental Activities of Daily Living (IADL) stage patterns of association between different types of mental and physical conditions. Patterns of association of ADL and IADL stages with different type(s) of mental and physical chronic health conditions. A multinomial logistic regression was applied to address type of condition. Absence of the condition served as reference for each type of condition. Each plotted association was adjusted for age, sex, race/ethnicity, and all other conditions. Relative risk ratios are indicated at the central points with the vertical lines representing 95% confidence intervals. All relative risk ratio estimates were weighted applying 2006 sample weights. Each set of 4 vertical lines shows stage I, II, III, or IV compared to stage 0 (no limitation). The Y axis shows the logarithm of relative risk with estimates weighted applying 2006 sample weights.

Figure 2.

(a) Activities of Daily Living (ADL) stage patterns of association with perceived health status. (b) Instrumental Activities of Daily Living (IADL) stage patterns of association with perceived health status. Patterns of association of ADL and IADL stages with perceived health status rated by individual or proxy referenced to individuals of the same age as excellent (reference), very good, good, fair, or poor. Excellent perceived health served as reference. Comparisons were according to ADL-0 and IADL-0 as reference. Each set of 4 vertical lines shows stage I, II, III, or IV compared to stage 0 (no limitation). The Y-axis shows the relative risk with estimates weighted applying 2006 sample weights.

Table 1

Comparison of ADL and IADL questions in the Medicare Current Beneficiary Survey (MCBS) to those in the Second Longitudinal Study of Aging (LSOA II)

	Medicare Current Beneficiary Survey (MCBS)	Second Longitudinal Study of Aging (LSOA II)
Introductory instructions	Now I'll ask about some other everyday activities. I'd like to know whether (you have/SP has) any difficulty doing each one by (yourself/ himself/ herself) and without special equipment.	These questions are about some other activities and how well you are able to do them by yourself and without using special equipment.
Lead in	Because of a health or physical problem, (do you/does SP) have any difficulty with the following?	First asked: Because of a health or physical problem, (do you/does SP) have ANY difficulty—yes/no? Second asked: If yes, followed by how much difficulty: some, a lot, or unable?
Activities of Daily Living	Eating Toileting Dressing (Note putting on socks or stocking included in documentation.) Bathing or showering Getting in or out of bed or chairs Walking ^a	Eating Using the toilet, including getting to the toilet Dressing Bathing or showering Getting in or out of bed or chairs Walking
Instrumental Activities of Daily Living	Using the telephone Managing money (like keeping track of money or paying bills) Preparing his/her own meals Light housework (dishes, straightening up, or light cleaning) Shopping for personal items (such as toilet items or medicines) Heavy housework (like scrubbing floors or washing windows)	Telephoning Managing money (keeping track of money and paying bills) Meal preparation Light housework (dishes, straightening up, or light cleaning) Shopping (for groceries, personal items, or medications) Heavy housework (scrubbing floors or washing windows)
For IADL if answer is "Does not do"	Coded as difficult if reason was because of a health reason. Coded as not difficult if reason was not caused by a health reason.	Is this because someone else normally does the activity? If yes, coded as not necessary.

ADL = Activity of Daily Living; IADL = Instrumental Activity of Daily Living; MCBS = Medicare Current Beneficiary Survey; LSOA = Longitudinal Study of Aging; SP = sample person.

^aWalking in the MCBS is listed among the Activity of Daily Living questions. Its definition includes using walls or furniture for support.

Table 2
ADL and IADL stage threshold definitions (*italicized*) for the Medicare Current Beneficiary Survey

Limitation Expressed as Difficulty	ADL Stage	IADL Stage
0 = None	Can eat, toilet, dress, bathe/shower, get in/out of bed/chairs, and walk without difficulty.	Can use the telephone, manage money, prepare meals, do light housework, shop for personal items, and do heavy housework.
I = Mild	Eating, toileting, dressing, and bathing/showering are not difficult. (May have difficulty getting in/out of bed/chairs and/or walking)	Using the telephone, managing money, preparing meals, and doing light housework are not difficult. (May have difficulty shopping for personal items and/or doing heavy housework)
II = Moderate	Eating and toileting are not difficult. (May have difficulty dressing, bathing/showering, getting in/out of bed/chairs, and/or walking)	Using the telephone and managing money are not difficult. (May have difficulty preparing meals, doing light housework, shopping for personal items, and/or doing heavy housework)
III = Severe	Difficulty with eating and/or toileting but not with all ADLs.	Has difficulty using the telephone and/or managing money but not all IADLs are difficult.
IV = Complete	<i>All ADLs are difficult.</i>	<i>All IADLs are difficult.</i>

Getting in/out of bed/chairs in the intermediate difficulty category in the Second Longitudinal Study of Aging stages moved to the most difficult category in the Medicare Current Beneficiary Survey stages, and bathing/showering moved from the most difficult into the intermediate category. There were no differences in the IADL stage hierarchy.

ADL = Activity of Daily Living; IADL = Instrumental Activity of Daily Living.

Table 3
ADL and IADL estimated population size and prevalence in the 2006 community-dwelling Medicare population according to stages of activity limitation

Stage (Degree of Difficulty)	Difficulties in ADLs		Difficulties in IADLs	
	Estimated ^a N in Population (Millions)	Weighted %	Expected N in Population (Millions)	Weighted %
0 = None	26.3	69.5	22.9	60.5
I = Mild	6.0	15.9	6.5	17.2
II = Moderate	2.9	7.6	3.5	9.2
III = Severe	2.2	5.7	4.1	10.8
IV = Complete	0.5	1.3	0.9	2.3
Total	37.9	100	37.9	100

ADLs = Activities of Daily Living; IADLs = Instrumental Activities of Daily Living.

Source: Authors' tabulation using the Medicare Current Beneficiary Survey.

^a Calculated using survey weights designed to give estimates representative of the Medicare Population.

Table 4
Prevalence of individual characteristics and health condition by ADL and IADL limitation status (yes/no) within the community-dwelling adult Medicare population in 2006

Characteristic/Condition	Total Raw N (Weighted %)	ADL Stage 0 Weighted %	ADL Stage >0 Weighted %	IADL Stage 0 Weighted %	IADL Stage >0 Weighted %
Age, y					
1: <65	2578 (15.5)	11.8	23.8	8.0	26.9
2: 65-80	7700 (60.4)	67.8	43.5	72.2	42.3
3: >80	4454 (24.1)	20.4	32.7	19.8	30.8
Gender					
Male	6687 (44.8)	46.5	41.0	50.3	36.5
Female	8045 (55.2)	53.5	59.0	49.7	63.5
Race/ethnicity					
1: NH white	12,288 (83.8)	84.9	81.2	85.5	81.2
2: NH black	1464 (9.4)	8.7	11.2	8.3	11.2
3: Hispanic	273 (1.9)	1.8	2.2	1.7	2.3
4: Other	707 (4.9)	4.6	5.4	4.6	5.3
Condition					
Stroke	2049 (13.3)	9.0	23.1	8.5	20.7
Dementia	570 (3.5)	2.0	7.0	1.3	6.9
Osteoporosis	2883 (19.6)	16.9	25.6	15.7	25.4
Diabetes	2665 (18.9)	16.0	25.7	15.7	24.0
Cardio-pulmonary	7125 (47.5)	18.4	58.3	27.9	57.3
Arthritis	8562 (58.3)	52.0	72.5	51.1	69.3
Cancer	2601 (17.5)	16.7	19.4	16.2	19.5
Psychiatric	2793 (18.3)	13.6	29.2	10.0	31.1
Hypertension	9228 (62.8)	59.8	69.7	59.3	68.3
General health status					
1: Excellent	2117 (15.1)	19.8	4.3	21.6	5.1
2: Very good	3883 (26.6)	31.7	15.3	33.8	15.8
3: Good	4679 (31.3)	31.5	31.2	31.5	31.2
4: Fair	2736 (18.0)	13.1	29.3	11.0	28.9
5: Poor	1254 (8.5)	3.7	19.6	1.9	18.7

ADL = Activity of Daily Living; IADL = Instrumental Activities of Daily living; NH = non-Hispanic.

Source: Authors' tabulation using the Medicare Current Beneficiary Survey.

^aCalculated using survey weights designed to give estimates representative of the Medicare Population.