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Staging Activity Limitation and Participation Restriction in Elderly Community-Dwelling Persons According to Difficulties in Self-Care and Domestic Life Functioning

Margaret G. Stineman, MD, John T. Henry-Sánchez, MD, Jibby E. Kurichi, MPH, Qiang Pan, MA, Dawei Xie, PhD, Debra Saliba, MD, MPH, Zi Zhang, MD, and Joel E. Streim, MD

Department of Physical Medicine and Rehabilitation, Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania (MGS, JTH-S); Department of Biostatistics and Epidemiology, Center for Clinical Epidemiology and Biostatistics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania (MGS, JEK, QP, DX, ZZ); Greater Los Angeles VA GRECC, UCLA/Jewish Home Borun Center for Gerontological Research, RAND, Santa Monica, Los Angeles, CA (DS); Geriatric Psychiatry Section of the Department of Psychiatry, Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania (JES); and VISN 4 MIRECC, Philadelphia Veterans Affairs Medical Center, Philadelphia, Pennsylvania (JES)

Abstract

Objective—This study aimed to describe the conceptual foundation and development of an activity limitation and participation restriction staging system for community-dwelling people 70 yrs or older according to the severity and types of self-care (activities of daily living [ADLs]) and domestic life (instrumental ADLs (IADLs)) limitations experienced.

Design—Data from the second Longitudinal Study of Aging ($N = 9447$) were used to develop IADL stages through the analyses of self- and proxy-reported difficulties in performing IADLs. An analysis of activity limitation profiles identified hierarchical thresholds of difficulty that defined each stage. IADL stages are combined with ADL stages to profile status for independent living.

Results—IADL stages define five ordered thresholds of increasing activity limitations and a “not relevant” stage for those who normally have someone else do those activities. Approximately 42% of the population experience IADL limitations. To achieve a stage, a person must meet or exceed stage-specific thresholds of retained functioning defined for each activity. Combined ADL and

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Correspondence: All correspondence should be addressed to: Margaret G. Stineman, MD, Center for Clinical Epidemiology and Biostatistics, Perelman School of Medicine, University of Pennsylvania, 423 Guardian Drive, 904 Blockley Hall, Philadelphia, PA 19104-6021.

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IADL stages define 29 patterns of activity limitations expressing the individual's potential for participating in life situations pertinent to self-care and independent community life.

Conclusions—ADL and IADL stages can serve to distinguish between groups of people according to both severity and the types of limitations experienced during home or outpatient assessments, in population surveillance, and in research.

Keywords

Independent Living; Aging; Daily Living Activities; ICF

The International Classification of Functioning, Disability, and Health (ICF) is fast becoming the international standard for describing health and disabilities.¹ The ICF defines *activity limitations* as difficulties encountered when people perform a task and *participation restrictions* as problems individuals encounter when engaging in life situations. Although many taxonomies express disability concepts, the Institute of Medicine² recently recommended using the ICF as the conceptual framework for developing a comprehensive disability monitoring system. Moreover, the National Committee on Vital and Health Statistics (NCVHS) argued that it is essential to produce comparable functional status measures across care settings that are similar to International Classification of Diseases-9-Clinical Modification and International Classification of Diseases-10 for diagnoses.³ Therefore, we developed a staging system for activities of daily living (ADLs),⁴ applying terminology from the ICF and data from the second Longitudinal Study of Aging (LSOA II). The ADL questions are self- or proxy-reported, making it feasible to acquire information on large populations through telephone or in-person interview formats, where measurements based on clinician-observed performance would be too labor intensive. The ADL system includes five stages of increasing limitations defining discreet “patterns of retained function.” The tasks within the ADL stages express sets of activity limitations consistent with the ICF “self-care” chapter. Each stage reflects ICF qualifiers beginning with stage 0 (no limitation) and concluding with stage IV (total limitation; unable to do any ADLs).⁴ To be at a particular stage, individuals must be functioning at or better than specified levels across individual ADLs. In addition to severity, stages group people in ways that place a ceiling on the amount of difficulty they can experience when performing each ADL. We demonstrated that people at higher stages of ADL limitation are more likely to have health conditions such as stroke known to be disabling.⁴ In addition, stages show predictive validity with regard to short- and long-term mortality, with median survivals ranging from 1.6–10.6 yrs.⁵

THEORETICAL FOUNDATIONS

Person-level functioning (activity) is recognized as partially hierarchical.^{6–11} Therefore, we assume certain profiles or thresholds of function that are more clinically plausible (or likely) than others across ADLs. Although there may be several underlying ADL hierarchies,⁶ Figure 1 shows the most commonly reported ordering as compiled across common measures.^{7,8,11} “Harder” activities tend to become difficult early in the course of physical and cognitive disabilities, whereas “easier” activities remain intact until late. Evidence supporting this ontologic order for ADLs emerged through Katz et al.’s¹² theoretically grounded Index of ADL. This order has further been supported by later measures (Fig. 1).^{7,8,10,11} For example, eating and continence, which tend to be lost late, are distinct from activities such as bathing and dressing that are lost earlier in old age.⁶ The order for ADLs appears consistent across the measures, except for getting out of bed or chair, which is at two positions, most likely depending on how questions about transferring are worded. ADL stage thresholds reflected this order as shown in Figure 1, with getting in or out of bed or chair following the hierarchy of the Functional Disability Screen¹⁰ and the Physical Self-

Maintenance Scale (PSMS)⁷ rather than the Index of ADL and Functional Independence Measure.^{8,12,13}

Recognizing need to measure more advanced activities, Lawton and Brody⁷ established instrumental ADLs (IADLs) to express functions important to managing one's life circumstances in the community. Factor analytic studies applying more than 100,000 persons drawn from the US population statistically confirmed the separation of ADL and IADL.¹⁴ Long recognized by the geriatric literature as distinct dimensions,¹⁵ IADLs are included in the "domestic life" ICF chapter. IADLs compared with ADLs require more complexly organized locomotor, neurologic, and executive functioning; involve greater environmental interaction and performance abilities; and are generally lost earlier.^{9,16} Seeing these more complex skills, in addition to ADLs, as important if older people are to live autonomously in the community, we derive and test IADL stages as companion to ADL stages. Based on a review of existing measures,^{7,10} we anticipate that thresholds of function across empirically derived IADL stages will mirror the expected order as hypothesized in the last column of Figure 2. The addition of IADL to ADL stages forms a two-dimensional Activity Limitation Staging system expressing both the severity and types of activities limited across the broad self-care and domestic life domains.

The ICF defines disability as encompassing impairments, activity limitation, participation restriction, personal factors, and environmental factors. The ICF was developed as a framework to code information about health and disability, not as a model to explain the dynamic nature of disablement.¹⁵ Therefore, we apply the biopsychosocial model as a theoretical foundation for specifying and testing hypotheses about construct validity.¹⁷ These explanatory hypotheses¹⁸ establish the degree to which IADL stages are associated with other observable variables that theoretically should relate to additional concepts.^{16,19} Recognized as fundamental to rehabilitation practices,²⁰ the biopsychosocial model expands on the biomedical and biopsychosocial models²¹ addressing how environmental elements, along with illness and injury-related impairments, link to disability. We expect that higher stages of ADL limitation will be associated with older age and perceptions of poor health. Although a history of stroke will lead to impairments strongly associated with IADL stage, hypertension will not. Finally, we anticipate that the proportions of people who perceive unmet needs for accessibility features in the home will increase but that based on patterns shown in ADL stages,⁴ unmet needs will reach a plateau and possibly decline at the highest stages.

Existing ADL and IADL Measurement Approaches

Stages measure disability globally and will thus be most appropriated to population statistics intended to address the broad functional consequences of health problems.²² ADL and IADL questions are aggregated into global disability measures in several ways. The simplest monitors the presence or absence of limitations across ADLs and IADLs dichotomously.²³ Others express severity as an average of multiple ratings¹³ or as simple counts of activity limitations.²⁴ Recent efforts explore item response theory and item banking to more precisely measure persons' severity along a broader functional continuum.²⁵ Staging was developed based on the recognition that typical global measures of activity limitation that express severity by counting, summing, or otherwise aggregating responses across diverse activities obscure the types of activities limited. Even with sophisticated item response theory measures, the types of activities limited become obscured through the processes of combining information from the multiple activities necessary to estimate severity. It is impossible to see from a score or measure which activities individuals are still able to perform. However, knowing which activities people can still do is relevant. For example, the subjective life experiences and the types of care needed by people unable to telephone will differ from those unable to shop.

Activity Limitation Staging builds on Functional Independence (FI) staging²⁶ established for inpatient rehabilitation and on staging applying the Activity Measure for Postacute Care.²⁷ All three approaches reflect functional hierarchies. Activity Measure for Postacute Care staging applies an item response theory–derived interval measure from which stages of function are defined from cut scores of increasing ability.²⁸ Both Activity Limitation Stages and Activity Measure for Postacute Care stages apply ICF concepts.

FI stages predict a variety of outcomes among patients undergoing inpatient rehabilitation or skilled nursing level rehabilitation,^{29,30} are sensitive to change,²⁶ and show associations between more intensive therapy and better functional outcomes.^{31,32} Intended to reflect older community-dwelling people who might be seen as outpatients or in-home care rather than as rehabilitation inpatients, Activity Limitation Stages differ from FI stages by characterizing person- (self- or proxy-) reported rather than clinician-rated functional information. The use of self- or close proxy-report recognizes growing emphasis on person-centered care and self-reported ratings as being valid and important.²⁵

Activity Measure for Postacute Care stages profile peoples' expected abilities in ways that help users understand the kinds of activities individuals may be able to do at each stage; however, actual status is not specified. In contrast, Activity Limitation Stages specify actual rather than expected status. The specific ADLs and IADLs individuals are able to accomplish without difficulty and the maximum difficulty experienced for the remaining activities are known.

METHODS

Sample

The participants ($N = 9,447$) were a nationally representative sample from the LSOA II baseline conducted in 1994. The LSOA II is a complex multistage cohort of community-dwelling, noninstitutionalized sample persons 70 yrs or older at the time of the baseline interview and is linkable to the 1994–1995 National Health Interview Disability Supplement.^{33–35} The National Health Interview Disability Supplement contains information about disabilities at a depth that has not been repeated in linkable surveys. Proxy respondents were used 15.2% of the time, with cognitive impairment being the most common reason for use. The current analysis obtained institutional review board approval from the University of Pennsylvania.

Variables

The six ADLs, ordered by expected increasing difficulty, include eating, toileting (including getting to the toilet), dressing, transferring (getting in and out of bed and chairs), bathing, and walking. These questions were applied to formulate ADL stages developed previously.⁴

The six IADLs, ordered by expected increasing difficulty, include telephoning, managing money (keeping track of money or paying bills), meal preparation, light housework (dishes, straightening up, or light cleaning), shopping (for groceries or personal items), and heavy housework (scrubbing floors or washing windows).

The item responses for each ADL and IADL were scored 0 to 3 to be consistent with ICF performance qualifiers (0, no difficulty; 1, some difficulty; 2, a lot of difficulty; 3, unable). Table 1 shows specific wording for each ADL and IADL. The LSOA II questionnaire can be found at http://www.cdc.gov/nchs/data/series/sr_10/10_193_5.pdf.

Chronic conditions were reported by the respondent as diagnosed by a physician, including coronary heart disease (heart attack, myocardial infarction, or angina), other heart disease,

stroke, osteoporosis, diabetes, arthritis, bronchitis or emphysema, asthma, hypertension, and/or cancer. These were expressed according to the presence or absence of each condition.

Perceived health status was reported by the respondent as excellent, very good, good, fair, or poor.

Perceived home accessibility addressed the respondent's perceived unmet needs for one or more accessibility features in their homes, including widened doorways, ramps, kitchen modifications, railings, easy-open doors, accessible parking or drop-off sites, elevators or stair glides, alerting devices, or other special features.

Deriving the Stages

IADL stages were defined empirically applying approaches published previously for ADL stage and FI stage development.^{4,26} Face validity was addressed by comparing results (the expected order of loss) to the hierarchical orders shown in Figures 1 and 2 derived from previous research on the hierarchical structure of ADLs and IADLs.^{6–11} The most typical or expected order of IADLs was obtained from observed profiles in the data using Stata 11 (Stata Corp., College Station, TX).³⁶

Paralleling the five ADL stages (0 to IV), the five IADL stages (0 to IV) were labeled a priori to reflect the ICF generic qualifiers of absent or “no” activity limitation (Stage 0), mild limitations (Stage I), moderate limitations (Stage II), severe limitations (Stage III), and complete limitations (Stage IV).

Each stage defines a threshold of retained function that the individual must function at or beyond. This “stage threshold” places a ceiling on the amount of difficulty individuals can report for each activity within a domain and still be defined at a particular stage. The type of disability is expressed by the item responses in the stage threshold that states whether people experience difficulty with each component activity and, if so, places a ceiling on the amount of difficulty experienced. Higher Roman numeral stages express more severe disability.

To develop IADL stages, all unique IADL item-response profiles present in the data were reviewed. The profiles were sorted by the sum of their item responses ranging from 0 to 18 because there were six activities in each domain, and each activity can have “0,” “1,” “2,” or “3” as a response. This yielded 18 sets of item-response profiles. The first set was a single profile of all 0s defining Stage 0 (“no limitations”). The last set was a single profile of all 3s summing to 18 defining Stage IV (“complete limitations”). Stage I was formed by selecting the optimal profile from the set of all profiles in the data where the sum of item responses for the IADL activities was 6. The value 6 was selected because it represented the value that would occur if each of the six item response scores was 1 (indicating some difficulty). Stage II was defined by selecting the optimal profile from the set of all profiles in the data where the sum of item responses within the profiles was 12. The summed value of 12 was selected because it represented the value that would occur if each of the six item responses was 2 (indicating a lot of difficulty).

Many profiles will sum to 6 or 12 because of the permutations across the item responses. The task of identifying the optimal threshold profiles for stages I and II was directed at capturing the most typical pattern. To do this, we calculated the percentage of participants experiencing either the same or less difficulty for each activity. We calculated the percentage of all persons in the analytic data whose six IADLs were as or more functional than the item responses in each profile. These percentages represented the proportion of people in the full data who would meet Stage I or II if that profile were selected as the

threshold. The profiles associated with the largest percentage of participants formed Stages I and II.

Stage III (“severe limitations”) was defined by default to include all persons not meeting the Stage II threshold in one or more activities but still having some retained functioning, that is, having more abilities than Stage IV that is defined as inability in all activities. Stage III accommodates people with severe disabilities whose patterns of limitation do not follow the typical hierarchy.

We established a priori that the empirically derived stages must meet two criteria to achieve face validity. (1) The sequence of activity limitations across the thresholds of retained function defining the stages must reflect the expected orders of activity shown at the far right-hand side of Figures 1 and 2 moving from the least to the most limited stages.^{8,10,12} (2) Once an activity becomes difficult, it must remain difficult at more limited stages, with the exception of Stage III, which is intended to accommodate the disabilities of persons whose patterns of limitation are atypical of the hierarchy.

Prevalence Estimation

Prevalence across the stages and stage combinations was determined from the LSOA baseline data by applying sampling weights to those with complete data to enable projection of people 70 yrs or older expected to be living in US communities in 1994. In making prevalence estimates, we included those with complete ADL and IADL information as well as those who did not answer IADL questions because they did not normally do them. Therefore, the sum of sampling weights closely reflects the full population. Because the sample was limited to community-dwelling persons, we expected that the highest percentage of persons would be at the lowest stages of limitation. Because IADLs are more complex than ADLs, we expected that there will be few, if any, persons in the population with high stages of ADL limitation combined with no IADL limitation.

Construct Validity of IADL Stages

The construct validity of the IADL stages was tested empirically by addressing support or lack of support for the theoretically based hypotheses established a priori. Analyses consisted of cross-tabulations and significance testing between the stages and diagnostic conditions and other concepts expected to be associated with IADL stage.

RESULTS

There were only 130 of 9447 persons (1.4%) who failed to answer one or more ADL questions. In contrast, there were 1999 of 9447 (21.2 %) persons who did not answer one or more IADL questions. There were 1614 (80.7%) of 1999 persons who stated that they did not answer one or more IADL questions because another person typically performed the activity, that is, they were not seen as relevant to the individuals’ life circumstances. Therefore, ADL stages were derived from 9317 participants (98.6%) and IADL stages from 7448 persons (78.8%). The 385 persons who did not answer IADL questions and did not state that another person typically performs the activity(s) were considered missing information in the IADL analysis for the purposes of population projection. Tables 2 and 3 define the ADL and IADL stage thresholds. To be at a specific stage, people must be able to perform activities at least as functional as all the values associated with that stage. When a person normally does not perform IADLs, he or she is assigned to an IADL not relevant (IADL-NR) stage.

Face Validity

The ADL and IADL stages meet the two criteria set a priori, establishing face validity. The defined sequence of activity limitations across the retained functions associated with the ADL and IADL stages reflect the expected ontologic orders shown in Figures 1 and 2.^{8,10,12} By definition, people at IADL-I must be able to use the telephone, manage money, prepare meals, and do light housework without difficulty (Table 3). They may have difficulty or be unable to shop and/or do heavy housework. This is consistent with our expected hierarchy (Fig. 2). Shopping and heavy housework are consistently the most difficult items. People at IADL-II can still use the telephone and manage money, without difficulty suggesting that these are the easiest items. Preparing meals and doing light housework are items of intermediate difficulty as anticipated. The ADL hierarchy can be analyzed the same way using Figure 1. Once an activity becomes difficult, the threshold scores in subsequent stages remain at the same or greater difficulty levels through all subsequent ADL and IADL stages.

Prevalence Estimates of Stages and Activity Limitation Patterns

The weighted prevalence and the unweighted sample sizes for the ADL and IADL stages according to 1994 US population estimates are shown in Table 4. Among the community-dwelling US population 70 yrs or older, prevalence declined progressively as ADL and IADL stages increased in severity. Table 5 shows the 29 possible combinations of ADL and IADL stages. More than half (53.86%) of individuals can be expected to have no self-care or domestic life difficulties at ADL-0 and IADL-0. More than 3 million (15.29%) people can be expected to be classified in the three most prevalent patterns, representing mild disabilities. In contrast, only 0.38% of older community-dwelling people corresponding to less than 100,000 people were at the most severe pattern at ADL-IV and IADL-IV. Some ADL and IADL combinations did not appear clinically feasible such as ADL-IV in combination with IADL-0, IADL-I, or IADL-II (i.e., pattern 22, 23, or 24). For almost 3.6 million persons (17.36% of the population), IADL status was not seen as relevant because someone else in their lives normally did those tasks. An estimated 1.5 million persons at IADL-NR had ADL limitations.

Associations Between IADL Stage and Other Person- and Environment-Related Factors

Table 6 shows the degree to which age, sex, race, chronic illness burden, perceptions of illness, and unmet need for special accessibility features in the home relate to IADL stage. Stroke history and the need to use a proxy respondent because of Alzheimer disease or dementia showed the strongest associations with IADL stage. There were 4.0%, 9.2%, 18.1%, 22.0%, and 44.0% of individuals with stroke histories at IADL-0, IADL-I, IADL-II, IADL-III, and IADL-IV, respectively. Although less than 4% of community-dwelling older persons overall required a proxy respondent to provide information because of Alzheimer disease or dementia, 67.8% of those at IADL-IV required a proxy for that reason. As anticipated, hypertension was more likely among those with any IADL limitation (IADL-1, -II, -III, or -IV compared with IADL-0) but did not show an ordered increase in prevalence at increasing stages of limitation. Perceived health status was rated as excellent or very good among 47.8% of people at IADL-0 but only by 12.1% of people at IADL-IV. In contrast, health status was rated as poor in 2.5% of people at IADL-0 and by 41.0% of respondents at IADL-IV. The proportions of people at IADL-0, IADL-I, and IADL-II perceiving unmet need for environmental accessibility features were 1.7%, 9.2%, and 25.6% and then declined slightly to 20.7% and 21.4% at IADL-III and IADL-IV, respectively.

DISCUSSION

We developed IADL stages as a companion to ADL stages⁴ and confirmed face validity according to hierarchies of difficulty reported in the literature.^{8,10,12,37} Together, these two

domains comprise Activity Limitation Staging, which could provide a standard ICF-based disability monitoring system for describing self-care and domestic life limitations among older community-dwelling people. Recognizing problems distinguishing between the concepts,³⁸ stages are intended to blend across activity and participation through different levels of measurement.¹ Reported status in individual ADLs and IADLs detail activity limitation at the most granular level, specifying problems with individual tasks. ADL and IADL stages, each combining status across six activities, express tasks people are still able to perform across those domains. Combinations of ADL and IADL stages reflect patterns of participation relating to the co-occurrence of difficulties with self-care, and essential interactions with home and community environments (i.e., domestic life).¹⁹ Staging is not intended to replace descriptions of limitations across individual ADLs and IADLs or other approaches to measurement.²⁷ Knowledge about difficulties with individual tasks is essential when establishing detailed care plans for an individual. Stages summarize this detailed information globally,²² which, although still specifying the activities individuals can perform, will logically be more beneficial for screening, population surveillance, and prediction.

As in ADL stages,⁴ construct validity of the IADL stages was supported by demonstration of expected associations. Although the prevalence of hypertension did not increase beyond IADL-I, the likelihood of stroke history increased progressively with stage of IADL limitation. Age, perception of poor health, and the need to use a proxy respondent because of Alzheimer disease or dementia all showed direct increases with higher stages of IADL limitation. The perception of unmet needs for environmental accessibility features increased steadily among those at IADL-I and IADL-II, leveling off at IADL-III and IADL-IV, suggesting thresholds at which the need for environmental adaptation is likely recognized.

Around 5% of older US community-dwelling persons can be expected to have activity limitations that follow the typical order of difficulty and thus are assigned stage III. Examples include people with difficulties eating or toileting but not dressing or bathing and those with difficulties telephoning or managing money but not preparing meals or shopping. Eating and toileting are essential to survival, and these limitations are a more immediate threat than limitations in more complex ADLs. Similarly, telephoning and managing money are more fundamental to life autonomy than the more challenging IADLs. We placed people with nonfitting limitations at a third “severe” stage. This positioning was empirically supported by our finding that people’s likelihood of poor health and disabling conditions increased progressively from stages 0, I, II, III, and IV in both the ADL and IADL dimensions.⁴ IADL and ADL tasks have distinct implication to individuals’ potential to live successfully in the community. Although ADL activities involve self-care and intimate management of body functions, IADL tasks are managed in interactions with places outside one’s self and are more naturally delegated to others. Therefore, they can be functionally irrelevant to those with others who normally do them. Nearly a quarter of older community-dwelling persons in our study were living in circumstances where IADLs were normally done by others.

Healthy People 2020 objectives include initiatives to encourage community life and reduce the number of people with disabilities living in nursing homes.³⁹ Clinicians, health service researchers, and policy makers might use stages to establish and test alternative disability management strategies targeted at keeping people living at home longer. The success of such programs has implications to both the quality-of-life of older people and the overall economic solvency of society.

Staging Illustrations

Staging is illustrated using the following hypothetical examples.

Case 1—A 79-yr-old woman with insulin-dependent diabetes and right-sided stroke-related hemiparesis lives with her daughter (single working mother with 9-yr-old son). The home is accessible inside with 12 steps to exit.

She responds for ADLs, “I have no difficulty eating, toileting, dressing, or transferring from bed to chair. I have some difficulty bathing and walking.” For the IADLs, she indicates, “I have no difficulty telephoning or managing money but have some difficulty with meal preparation and a lot of difficulty with light housework. I am unable to shop or do heavy housework.”

Case 2—Case 2 has the same living circumstances and diagnoses as case 1, but her activity limitations differ as follows: her daughter, serving as proxy, states for ADLs, “My mother has no difficulty eating but has some difficulty toileting. She has a lot of difficulty dressing and transferring from bed to chair. She is unable to bathe and has a lot of difficulty walking.” For IADLs, she indicates, “My mother has a lot of difficulty using the telephone; she is unable to manage money, prepare meals, do light or heavy housework, or shop.”

Case 3—This man has the same living circumstances and diagnoses as case 2, but his activity limitations differ. His wife, serving as proxy, states that he is unable to eat and has some difficulty dressing and bathing but only some difficulty transferring and walking. She notes that none of the IADL activities are relevant because she normally does them.

To assign ADL and IADL stages, answer the clinical questions in Table 1 using the ADL and IADL definitions from Tables 2 and 3. Beginning with stage 0, move down the stages until all answers are true.

Case 1: ADL-I; IADL-II.

Case 2: ADL-II; IADL-III.

Case 3: ADL-III; IADL-NR.

Potential Clinical Applications for Screening and Population Surveillance

All cases had stroke and diabetes. The first two have identical histories showing distinctions between people with similar diagnoses and social and physical home environments but different stages. Capable of phoning for help, toileting herself, and walking (with difficulty), case 1 at ADL-I; IADL-II might be safely left alone for portions of the day. Case 2 at ADL-II; IADL-III, in comparison, would be at risk if left alone. Presumably needing to make tough choices between working *vs.* hiring care-givers, case 2's daughter, compared with case 1's daughter, will experience greater burden. Had case 2 been a 79-yr-old man living with his healthy 74-yr-old wife, the implication of the same disability could differ strikingly. If his wife is capable of being his primary caregiver and is normally home during the day, his daughter will be better able to attend to her child rearing and work responsibilities. Case 3's disability at ADL-III falls outside the typical hierarchy. He experiences more difficulty eating (typically the easiest ADL) than walking (generally the most difficult). This pattern can occur with stroke or other conditions where swallowing or arm(s) are affected disproportionately to legs. Although we do not know about his IADL status, knowledge that he is at IADL-NR is valuable because it indicates the availability of someone to provide functional assistance.

It is important to recognize life contexts such as sex and available support networks when applying IADL stages because they make most sense for those for whom the performance of IADLs is relevant. Definition of the IADL-NR stage allowed us to capture the statistical weights of those for whom IADLs were not relevant. Alternatively, multiple imputation⁴⁰

could be applied to predict what peoples' IADL stages would have been from other information about them, assuming they were living in circumstances where they did not have someone normally doing the activities for them.

The stages provide a broad look at individual patients according to their aggregate self-care and domestic life functioning. Accordingly, activity limitation staging might be applied routinely for screening older people during outpatient or home visits by either the individual or family members answering simple questions about ADLs and IADLs (Tables 2 and 3). Using staging in this fashion becomes analogous to a functional review of systems informing areas needing more detailed needs assessment and treatment planning. In addition, integrated systems such as patient-centered medical homes or federally funded area agencies on aging⁴¹ might routinely stage persons at entry, applying stages as decision support for referral to preventive, rehabilitative, and supportive services. Broad assessment and management plans and guideline development might be targeted to particular ADL and IADL stages with population-level results continuously monitored through electronic medical records. Serial staging of individuals could monitor functional trajectories and facilitate communication within and across healthcare practitioner teams caring for populations of older community-dwelling people enhancing continuity of care. With declining proportions of younger persons in the US population potentially available to provide care, clinicians will be increasingly called upon to help match limited resources to the needs of people, their families, and their home environments.

Although empirical work in the future will be essential to confirm our assumptions, we believe that alternative combinations of ADL and IADL stages have distinct clinical implications to patients, families, and society. For example, at ADL-0; IADL-I, the most frequent limitation pattern in the elderly US population, there are no self-care difficulties and only limitations with the most complex domestic life chores of shopping and/or heavy housework. In contrast, at ADL-I; IADL-II people can be expected to have some difficulty dressing and/or transferring, and up to a lot of difficulty with the hardest ADL tasks i.e., bathing and/or walking. Able to manage money and use the telephone, these individuals can still exercise autonomy over their personal affairs, but will experience problems performing routine IADLs such as light housework. This suggests need for daily but not necessarily 24 hour assistance or supervision. With ADL-IV; IADL-IV, autonomy for independent living is lost and care burden is maximized with inability to perform all self-care and domestic life tasks.

Potential Research Applications

FI and Activity Limitation Staging were inspired by Tumor, Nodes, Metastases cancer staging,⁴² which led to revolutionary developments in therapeutic oncology. Tumor, Nodes, Metastases stages define explicit clinically meaningful physiologic states marking both the severity and nature of the tumor, nodes, and metastases. ADL and IADL stages, through defined thresholds of functioning, provide concise dichotomous indicators. These indicators could form functionally homogenous strata of people for studying the effects of various interventions in trials. Although in oncology, T1-N0-M0 indicates a small tumor with no evidence of nodal involvement or metastasis, Activity Limitation Staging defines explicit and clinically meaningful functional states that mark both the severity and nature of disability across domains of ADLs and IADLs. Counts of activity limitations or aggregated scores express the severity of disability. A person who has two IADL limitations has more severity than someone with one limitation, but this count says nothing about the individual's retained function. Similarly, a person at IADL-II has more severe disabilities than someone at IADL-I, but in addition to expressing severity, the stages document different tasks people are still able to perform. When combining information across the Tumor, Nodes, Metastases domains, the oncologist gains insight about the overall status of the individual's cancer.

Likewise, combining information across the ADL and IADL stages can provide clinical insight into the overall status of the individual's disability. The Tumor, Nodes, Metastases categorization has undergone extensive testing. In parallel, the predictive validity of ADL and IADL stages will need testing in support of its usefulness. In contrast to the extremes of cure or death typically addressed in oncology, Activity Limitation Stages might be applied to predict functional recovery or losses relevant to quality-of-life.

Potential Policy Applications

Anticipated exhaustion of the Medicare trust fund by 2019⁴³ and baby boomers' needs for long-term care, coupled with the Supreme Court's 1999 Olmstead decision to offer services in "the most integrated setting" appropriate to individuals' needs, highlights the importance of establishing cost-effective home- and community-based services.⁴⁴ Moreover, the National Strategy for Quality Improvement in Health Care includes a mandate to address gaps in data aggregation techniques to measure the results of efforts targeted to improving the delivery of health care, patient health outcomes, and population health.⁴⁵

As illustrated by the clinical case scenarios, people at different stages can be expected to need different resources and supports. The weighted population prevalence estimates across the stages specify level and quality of demand for care in the older US community-dwelling population. Tables 4 and 5 provide snapshots of the extent and types of expected care needed by the entire older community-dwelling US population at the stage and stage combination levels. Although 1994 prevalence estimates cannot be generalized to today's population, knowledge of current stage distributions might be applied to project the broad needs of distinct groups of people today. There are millions of mildly limited people but only thousands at the most severe stages. Therefore, society's total expenditures for care of the more mild could exceed expenditures for the more limited even though per-individual costs of the later might be higher. Functionally homogeneous strata might also serve to forecast need. For example, unmet population needs for home accessibility features accelerating at IADL-I and peaking at IADL-II suggest needs to screen people at these stages.

This study has limitations. It is not realistic to expect all older individuals to be able to answer questions about status. Although close family member proxies might not always reflect what the individual would have said, correlations between self- and proxy-rated function are high,^{46,47} and excluding people who do not report for themselves biases prevalence more than including information from proxies.⁴⁸ Although the patient (or close proxy) voice is fundamental, self-report is distinct from functional measurements based on clinician-observed performances.^{13,26} Self-report measures cannot replace observational measures and vice-versa.

The age of the LSOA II data is concerning. We selected LSOA II data because of their linkage to the National Health Interview Disability Supplement. We could find no other source of national data that included such breadth and depth of information about disability, health conditions, and the physical and social environments within which people live. Field tested by the National Center for Health Statistics questionnaire design research laboratory before use, the ADL and IADL questions would be suitable for collection during outpatient clinical visits or for population surveys of older community-dwelling people.

Although Lazaridis et al., using data from the earlier LSOA I, confirmed that ADLs, as arranged within the Katz hierarchy and reflected in our stages, satisfied traditional requirements of scalability for forming a hierarchy,³⁷ their analyses uncovered four additional hierarchies, suggesting heterogeneity. Moreover, in contrast with ADL and IADL stages for which mobility domains could not be psychometrically justified,^{4,14} FI stages

having different questions include separate domains for mobility and self-care¹¹ consistent with recent measures distinguishing lower limb function.^{49,50} Future research will undoubtedly identify condition-specific hierarchies or those reflecting dimensions of different functional status measures. The ADL and IADL dimensions were supported within the particular questions and data set applied in our study.⁴⁸ Measures consisting of different questions or wordings will likely reflect alternative hierarchies or even dimensions. As an example, although persons responding to the English language version of the National Health and Retirement Survey reported walking difficulties most frequently, Hispanics responding to the Spanish-translated version reported dressing difficulty most frequently.⁵¹ This suggests that the translated version did not measure walking limitations the same way. Further studies on linguistic and cultural group differences will be essential.

CONCLUSIONS

We present Activity Limitation Staging as a tool for patient screening, research, and population surveillance that we anticipate will prove useful in guiding the assessment and referral of older community-dwelling patients to restorative therapy and supportive services. With population aging, disability management represents one of the greatest challenges in health care. We anticipate that ADL and IADL stages will be prognostic for various adverse outcomes including risks of falling, institutionalization, and mortality for which we already have evidence.⁵ Further studies will be needed to explore the prognostic implications of the alternative stages and these applications. Just as the field evolved to uncover specific stage sets for particular types of cancer, future research on disability staging will likely yield alternative stage sets reflecting specific disabling conditions and environments.

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	Index of ADL (1963)	PSMS (1969)	FIM™ (1994)	Functional Disability Screen (2000)	Expected hierarchy of ADLs within the staging system applying LSOA II questions
Least Difficult	Feeding	Feeding	Eating	Feeding Self	Eating
	Transferring	—	Transferring	—	Getting in or out of bed or chair (?)
	Going to Toilet	Toilet	Toileting	Using the Toilet	Using the toilet, including getting to the toilet
	Dressing	Dressing	—	Dressing	Dressing
	—	—	—	Transferring	Getting in or out of bed or chair (?)
	Bathing	Bathing	Bathing	Bathing	Bathing or showering
Most Difficult	—	Ambulation	Walking/wheelchair	Walking	Walking

FIGURE 1.

Known and expected ADL stage hierarchies. This figure shows the a priori derived expected ADL order as projected from known item difficulties and probabilities of limitation from published studies. This order was used to establish face validity of ADL stages after they were empirically derived. The expected ADL orders shown in the table derived from published measures with items similar to the LSOA II only show the items from these measures that mirror the activities included in the LSOA questionnaire. Included were five activities within the Index of ADL (Katz), five activities from the PSMS (Lawton), five activities of the FIM (Granger; Linacre), and six activities from the variables used to develop the Functional Disability Screen (Saliba) arranged in tabular columns beginning with the easiest and ending with the most difficult activities. The expected hierarchical order for the LSOA II activities used to formulate the ADL stages is included in the column to the far right comparing across the measures. The relative position of the transferring activity was less certain because of a discrepancy in the published literature, so its position is postulated as being in one of two places within the order as indicated by the question marks. The FIM distinguishes between dressing the upper and lower body and thus could not be compared with the single LSOA II dressing variable. LSOA II, second Longitudinal Study of Aging; PSMS, Physical Self-Maintenance Scale; FIM, Functional Independence Measure; ADL, activities of daily living.

	IADL (1969)	Functional Disability Screen (2000)	Expected hierarchy of IADLs within the staging system applying LSOA II questions
Least Difficult	Ability to use telephone	Using the telephone	Using the telephone
	Ability to handle finances	Managing Finances	Managing your money, such as keeping track of expenses or paying bills
	Food Preparation	Preparing Meals	Preparing your own meals
	—	Doing light housework	Doing light housework like doing dishes, straightening up, or light cleaning
	Shopping	Shopping	Shopping for groceries and personal items, such as toilet items or medicines
Most Difficult	—	—	Doing heavy housework, like scrubbing floors, or washing windows

FIGURE 2.

Known and expected IADL stage hierarchy. This figure shows the a priori derived expected IADL order as projected from known item difficulties and probabilities of limitation from published studies. This order was used to establish the face validity of IADL stages after they were empirically derived. The expected IADL orders shown in the table derived from published measures with items similar to the LSOA II only show the items from these measures that mirror the activities included in the LSOA questionnaire. Included were four activities from the PSMS (Lawton) and six activities from the variables used to develop the Functional Disability Screen (Saliba) arranged in tabular columns and beginning with the easiest and ending with the most difficult activities. The expected hierarchical order for the LSOA II activities used to formulate the IADL stages is included in the column to the far right comparing across the measures. LSOA II, second Longitudinal Study of Aging; PSMS, Physical Self-Maintenance Scale; IADL, instrumental activities of daily living.

TABLE 1**ADL and IADL wording definitions**

There are self and proxy versions of the questions. The level of difficulty score for each ADL and IADL is obtained based on the answers to two questions about each activity.   Self version   Question 1: "Because of a health or physical problem do you have any difficulty...."   Responses: Yes, no, don't do for health reasons, not ascertained, does not know or refused. If the person replied "no," then he or she is rated as having 0 difficulty in doing the activity.   Question 2: "How much difficulty do you have: some, a lot, unable to do it?"   Responses: (1) Some, (2) A lot, (3) Unable, not ascertained, does not know or refused, not applicable.   Proxy version   Question 1: "Because of health or physical problems does (name) have difficulty...."   Only respondents who provide a "yes" to question 1 are asked to provide a response to question 2. If the proxy replied "no," then (name) is rated as having 0 difficulty in doing the activity.   Question 2: Asks the respondent to rate difficulty according to one of the following categories: (1) Some, (2) A lot, and (3) Unable, not ascertained, does not know or refused or not applicable.   Six ADL activities   - Eating   - Getting in and out of bed or chairs   - Using the toilet, including getting to the toilet   - Dressing   - Bathing or showering   - Walking   Six IADL activities   - Using the telephone   - Managing money: keeping track of expenses or paying bills   - Preparing your own meals   - Shopping for groceries, personal items, medications   - Doing light work around the house: dishes, straightening up, and light cleaning   - Doing heavy work around the house: scrubbing floors or washing windows

ADL, activities of daily living; IADL, instrumental ADL.

TABLE 2

ADL stage threshold definitions

Stages of ADLs	Threshold Definitions for ADL Stages
ADL 0 (no difficulty): none; absent or negligible ADL limitation	Is the individual able to eat, toilet, dress, transfer, bathe, and walk without difficulty (all = 0)?
ADL I (mild difficulty): slight or low level ADL limitation	Is the individual able to eat and toilet without difficulty (=0), dress and transfer with no more than some difficulty (= 1), and bathe and walk with no more than a lot of difficulty (= 2)?
ADL II (moderate difficulty): medium or fair ADL limitation	Is the individual able to eat without difficulty (=0), use the toilet, dress, and transfer with no more than a lot of difficulty (e2), and possibly be unable to bathe and walk (= 3)?
ADL III (severe difficulty): high or extreme ADL limitation	Is the individual able to perform at least one ADL (i.e., eat, toilet, dress, transfer, bathe, or walk) with or without assistance but does not meet the defined threshold for stage II?
ADL IV (complete difficulty): total ADL limitation	The individual must be unable to eat, toilet, dress, transfer, bathe, and walk (all = 3)?

ADL, activities of daily living.

TABLE 3**IADL stage threshold definitions**

Stages for IADLs	Threshold Definitions for IADL Stages
IADL 0 (no difficulty): none, absent, or negligible IADL limitation	Is the individual able to use the telephone, manage money, prepare meals, do light housework, shop, and do heavy housework without difficulty (all = 0)?
IADL I (mild difficulty): slight or low level IADL limitation	Is the individual able to use the telephone, manage money, prepare meals, and do light housework without difficulty? May have difficulty or be unable to shop and/or do heavy housework (3).
IADL II (moderate difficulty): medium or fair IADL limitation	Is the individual able to telephone and manage money without difficulty (all = 0)? May have difficulty or be unable to prepare meals, do light housework, shop, and/or do heavy housework (3).
IADL III (severe difficulty): high or extreme IADL limitation	Is the individual able to perform at least one IADL (telephone, manage money, prepare meals, do light housework, shop, and/or do heavy housework) with or without difficulty (2) but does not meet the defined threshold for stage II?
IADL IV (complete difficulty): total IADL limitation	The individual must be unable to telephone, manage money, prepare meals, do light housework, shop, and/or do heavy housework (all = 3)?
NR-IADL: IADLs not relevant because someone else normally does the activities for them	Does someone close to the individual normally do one or more IADL task?

IADL, instrumental activities of daily living; NR, not relevant. Adapted with permission.⁴

TABLE 4

Sample number (unweighted) and weight-adjusted expected prevalence in the 1994 population

ADL Stages (n = 9317)	Sample Number^a	Total^b	Weighted %
0, no limitations	6675	15,463	72.0
I, mild limitations	1514	3461	16.1
II, moderate limitations	666	1516	7.1
III, severe limitations	416	917	4.3
IV, complete limitations	46	108	0.5
IADL Stages (n = 9062)^c	Sample Number^a	Total^b	Weighted %
0, no limitations	5186	11,998	58.0
I, mild limitations	1242	2842	13.7
II, moderate limitations	464	1038	5.0
III, severe limitations	441	975	4.7
IV, complete limitations	115	251	1.2
NR-IADL, not relevant	1614	3592	17.4

^aTotal number of cases applied to construct ADL and IADL stages.^bTotal number of cases projected to 1994 population after adjusting for missing data. To determine estimated population numbers, multiply by 1000.^cTotal number includes 7448 persons used to derive IADL stages and the 1,614 persons for whom IADLs were not relevant.

ADL, activities of daily living; IADL, instrumental ADL.

TABLE 5

Projected prevalence and numbers of persons according to ADL and IADL stage and stage combinations for community-dwelling people 70 yrs or older

	Stage Combination	Total ('000)	Weighted %
-	ADL-0; IADL-0	11,146	53.86
Mild restriction: at least one stage = I; none higher than I			
1	ADL-0; IADL-I	1428	6.90
2	ADL-I; IADL-I	1039	5.02
3	ADL-I; IADL-0	696	3.37
Moderate restriction: ADL and/or IADL = II; none higher than II			
4	ADL-I; IADL-II	384	1.86
5	ADL-II; IADL-II	333	1.61
6	ADL-II; IADL-I	304	1.47
7	ADL-0; IADL-II	137	0.66
8	ADL-II; IADL-0	108	0.52
Severe restriction: at least one stage = III; none higher than III			
9	ADL-0; IADL-III	265	1.28
10	ADL-I; IADL-III	245	1.18
11	ADL-II; IADL-III	228	1.10
12	ADL-III; IADL-III	222	1.07
13	ADL-III; IADL-II	184	0.89
14	ADL-III; IADL-I	72	0.35
15	ADL-III; IADL-0	47	0.23
Complete restriction: ADL and/or IADL must be stage IV			
16	ADL-III; IADL-IV	106	0.51
17	ADL-IV; IADL-IV	78	0.38
18	ADL-II; IADL-IV	43	0.21
19	ADL-I; IADL-IV	15	0.07
20	ADL-IV; IADL-III	16	0.08
21	ADL-0; IADL-IV	106	0.51
22	ADL- IV; IADL- 0	0	0.0
23	ADL- IV; IADL- I	0	0.0
24	ADL- IV; IADL- II	0	0.0
IADL not relevant			
25	ADL-0; IADL-NR	2050	9.91
26	ADL-I; IADL-NR	877	4.24
27	ADL-II; IADL-NR	409	1.98
28	ADL-III; IADL-NR	251	1.21
29	ADL-IV; IADL-NR	5	0.02

^aThere were an estimated 20.8 million persons in 1994 in the United States living in the community who were 70 yrs or older. A projected 15.3% (more than 3 million people) were expected to have mild, 6.1% (1.3 million people) were expected to have moderate, 6.1% (1.3 million) were expected to have severe, and 1.8% (364,000 people) were expected to have complete participation restriction. IADL stages were not considered relevant for 17.4% of the population (3.6 million people) because someone normally did those tasks. Stage combinations were grouped

descriptively by severity of overall restriction according to people being assigned to stages no higher than I, II, III, and IV according to status across the two dimensions. IADL-NR group was considered separately. Calculated applying 1994 data.

ADL, activities of daily living; IADL, instrumental ADL; NR, not relevant.

TABLE 6

Associations between instrumental activity of daily living stage and other person- and environment-related factors

	N = 7448	Stage 0 (n = 5186)	Stage I (n = 1242)	Stage II (n = 464)	Stage III (n = 441)	Stage IV (n = 115)
Age, mean (SD), yrs	75.9 (5.5)	75 (4.8)	76.9 (5.8)	77.6 (6.2)	80.2 (7.3)	81.7 (7.3)
Sex: $P < 0.0001$						
Male	2718 (37%)	42.8%	17.4%	27.2%	32.2%	43.5%
Female	4730 (63%)	57.2%	82.6%	72.8%	67.8%	56.5%
Race: $P < 0.0001$						
White	6403 (88.7%)	89.4%	88.9%	84.8%	86.2%	79.4%
Black	768 (7.4%)	6.6%	7.8%	9.9%	10.7%	12.9%
Other	277 (3.9%)	3.9%	3.2%	5.3%	3.1%	7.7%
Stroke						
Yes	554 (7.3%)	4.0%	9.2%	18.1%	22.0%	44.0%
No	6894 (92.7%)	96.0%	90.8%	81.9%	78.0%	56.0%
Hypertension: $P < 0.0001$						
Yes	3227 (42.7%)	38.8%	53.0%	54.1%	48.4%	41.2%
No	4221 (57.3%)	61.2%	47.0%	45.9%	51.6%	58.8%
Cardiopulmonary conditions						
Yes	2396 (32.3%)	25.4%	48.7%	53.0%	44.5%	41.8%
No	5052 (67.7%)	74.6%	51.3%	47.0%	55.5%	58.2%
Osteoporosis						
Yes	544 (7.7%)	4.7%	14.1%	17.9%	12.0%	14.7%
No	6904 (92.3%)	95.3%	85.9%	82.1%	88.0%	85.3%
Arthritis: $P < 0.0001$						
Yes	3390 (45.4%)	37.8%	66.3%	68.5%	55.9%	35.0%
No	4058 (54.6%)	62.2%	33.7%	31.5%	44.1%	65.0%
Diabetes						
Yes	874 (11.5%)	8.9%	16.1%	18.1%	20.6%	19.1%
No	6574 (88.5%)	91.1%	83.9%	81.9%	79.4%	80.9%
Cancer						
Yes	1205 (16.6%)	15.2%	21.5%	18.3%	17.1%	17.0%
No	6243 (83.4%)	84.8%	78.5%	81.7%	82.9%	83.0%

	N = 7448	Stage 0 (n = 5186)	Stage I (n = 1242)	Stage II (n = 464)	Stage III (n = 441)	Stage IV (n = 115)
Major mental illness						
Yes	67 (0.9%)	0.5%	1.2%	1.5%	2.3%	7.0%
No	7381 (99.1%)	99.5%	98.8%	98.5%	97.7%	93.0%
Use of proxy respondent because of Alzheimer disease or dementia						
Yes	300 (3.9%)	0.5%	2.1%	5.2%	31.5%	67.8%
No	7148 (96.1%)	99.5%	97.9%	94.8%	68.5%	32.2%
Perceived health status: $P < 0.0001$						
Excellent	1128 (15.5%)	19.4%	7.6%	3.7%	6.8%	4.8%
Very good	1771 (24.1%)	28.4%	16.9%	10.0%	11.9%	7.3%
Good	2591 (34.8%)	36.4%	34.7%	23.7%	29.0%	24.6%
Fair	1350 (17.6%)	12.8%	29.1%	30.0%	29.2%	22.4%
Poor	570 (7.5%)	2.5%	11.2%	31.8%	22.9%	41.0%
Perceived unmet home feature(s): $P < 0.0001$						
Yes	7008 (5.8%)	1.7%	9.2%	25.6%	20.7%	21.4%
No	440 (94.2%)	98.3%	90.8%	74.4%	79.3%	78.6%