



Bristol Activities of Daily Living Scale: a critical evaluation

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This article discusses the role of scales to measure activities of daily living, in particular in Alzheimer's disease, in the assessment and management of dementia. It explains the principles of activities of daily living measurement before introducing the reader to the Bristol Activities of Daily Living Scale. Many scales have been developed for measuring activities of daily living, but few were specifically designed for individuals with mild dementia living in the community for completion by caregivers. Fewer still were designed with the assistance of caregivers themselves. The article considers the use of the Bristol Activities of Daily Living Scale since its development and potential future changes. It also takes a longer look forwards at possible, more general advances in activities of daily living measurement.

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The diagnostic criteria for dementia require the measurement not only of cognitive ability, but also of functional skills. Indeed, loss of competence to carry out everyday occupational or social activities is a core feature without which the diagnosis cannot be made [1,2]. Commonly used screening tools, such as the Mini-Mental State Examination (MMSE) do not address this important noncognitive aspect of the progression of dementing disorders [3]. Furthermore, in addition to assisting with diagnosis, the measurement of functional abilities may help in assessing treatment effects and caregiver burden, identifying targets for rehabilitation or intervention, designing care packages and making decisions about nursing placement, and in exploring the time course of ability changes over the disease progression [4].

The term 'activities of daily living' (ADL) has been used to describe activities undertaken as part of daily functioning. These activities are often divided into basic or physical activities of daily living (basic ADL) and instrumental activities of daily living (IADL). Basic ADL usually include activities, such as: bathing, dressing, toileting, eating and drinking, dental hygiene and transferring from bed to chair. Basic ADL are hierarchical – that is, functions are ordered along a continuum,

with higher order or more complex abilities, such as toileting and bathing, being affected before less complex ones, such as eating and drinking [5,6]. Basic ADL are over learned, largely habitual and are generally free from cultural or educational bias [7].

IADL, by contrast, are complex and may involve social or environmental factors, as well as requiring the organization of a number of basic ADL for successful completion. IADL skills allow individuals to live independently and include activities, such as: shopping, food preparation and gardening, housework, managing finances, using transportation and using the telephone. IADL are more likely to be influenced by social or cultural factors than basic ADL. For example, preparing food requires the ability to buy the food, manage money, use transport and then to decide on a recipe and work through the steps to prepare it, all in an organized fashion. The ability to prepare food may also relate to the degree to which an individual previously undertook that task, so that gender, individual experiential, or other cultural factors are likely to influence performance. Unsurprisingly, IADL skills are those that tend to show changes earliest in the disease course and may be a greater source of frustration or difficulty for the individual with

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dementia. This is particularly important as loss of ability to perform ADL usually leads to loss of independence and the need for care from others. IADL are also those activities that are most likely to relate to changes in general cognitive ability, since cognitive skills of planning, judgement, organization and memory are essential to their successful completion [8]. Despite possible cultural bias in IADL, a recent survey of over 200 physicians from 11 countries in Australasia, Asia, Africa and Europe found broad agreement between different countries of origin on ranking of 12 ADL items (inside and outside mobility, hygiene, dressing, eating, medication, telephone use, housekeeping, finances, laundry, shopping and transportation [9]).

Although ADL skills, particularly IADL changes, may assist in diagnosis [10] and prediction of conversion to dementia [11], they also offer important information about the progression of disease and associated symptomatology in patients. ADL performance predicts rate of further cognitive decline and risk of mortality [12], as well as time to institutionalization in individuals with Alzheimer's disease (AD) [13]. Furthermore, along with behavioral features of dementia [14], deficits in ADL are one of the major causes of caregiver distress [15], although the relationships between ADL and caregiver burden and depression are less clearly established [16–18]. In addition, IADL performance has been shown to correlate significantly with self-reported depression in patients with AD [19,20].

Finally, in the absence of cures, assessment of ADL is an essential component of evaluating treatment or management. There is now clear recognition of the importance of ADL assessment in defining treatment success, particularly when using cholinesterase inhibitors [21–23]. This widening of view has found expression in the 1997, European Medicine Evaluation Agency (EMA) guidelines for trials of symptomatic treatments in AD [24]. These guidelines introduced two new concepts. The first, that an assessment of functional abilities may replace a global measure (such as a Clinician's Global Impression [25]) and the second, that stabilization in functional activities constitutes a positive response to treatment, especially in the context of an otherwise progressive disorder.

Having introduced the concept of ADL, this paper aims to familiarize the reader with some of the central issues in ADL measurement before introducing and discussing the Bristol Activities of Daily Living Scale (BADLS). It concludes with a more general exploration of potential developments in ADL assessment in dementia.

Features of optimal assessments

Validity, reliability & sensitivity to change

Optimally, ADL scales should have good face, construct and concurrent or convergent validity, as well as good inter-rater or test–retest reliability and they should also show sensitivity to change. Unfortunately, many commonly used ADL scales were designed without consulting the individuals usually caring for people with dementia – caregivers – or are currently used with populations for which they were not originally designed (e.g., the Barthel ADL Index [26] was developed for stroke patients

and the Nurses' Observational Scale for Geriatric Patients (NOSGER) [27] as an observational scale for use by nursing staff in an inpatient setting, although it has subsequently been validated for use by carers [28]). Although concurrent validity (the ability to distinguish between groups) may be useful in some settings (for example, the Blessed-Roth Dementia Scale [29] and the Functional Activities Questionnaire [30] were designed to distinguish between normal and abnormal aging) the ability to distinguish between levels of a condition is likely to be a more useful feature, since it makes it more likely that the measure will be sensitive to changing performance. Unfortunately, although a number of published ADL scales have been shown to have good inter-rater or test–retest reliability, few have demonstrable sensitivity to change or appropriate validity for the intended use of the scale [31].

Rated/measured by whom?

ADL scales can be divided into observational measures that require the person to perform an actual task and measures that ask either the individual with dementia themselves (self-report) or a caregiver or professional to rate capacity to perform tasks. In general, self-report scales are found to reflect actual ADL ability only in healthy or very mildly impaired individuals. In more moderate-to-severe dementia there is usually poor agreement [32]. Agreement between caregiver and patient and between caregiver and professional can also be problematic. Caregivers seem consistently to rate functional limitations on ADL as worse than professional nursing carers, even over a 6-month period [18] and they appear to overestimate the amount of time they spend in giving ADL assistance by comparison with observed time [33]. It is possible that family caregivers overestimate due to feelings of burden or depression, although ADL, depression and burden are not always correlated [18]. Alternatively, professional caregivers may underestimate ADL assistance because they are unfamiliar with the individual with dementia.

Most individuals with dementia live in the community, which makes both professional rating scales and observational scales largely impractical. With regard to observational measures, unless observed tasks are conducted using the individual's own equipment (kettle, taps etc.) in their own setting (e.g., their kitchen) and the tasks match activities they routinely carry out at home then performance measures may underestimate actual ability. In addition, performance anxiety may lead to lack of cooperation or distress. Finally, given that most individuals with dementia are cared for by family caregivers, these are the persons most familiar with their abilities. For these reasons, the most commonly used measures of ADL performance have required caregivers to rate the individual with dementia's capacity to perform tasks. The advantages and disadvantages of different rating techniques are summarized in TABLE 1.

BADLS

One ADL scale that matches many of the requirements outlined above is the BADLS [4]. The BADLS was developed with the assistance of caregivers of people with dementia in response

Table 1. Characteristics of different types of activities of daily living scale.

	Self-report	Care-giver report		Observed performance
		Family caregiver	Professional caregiver	
Takes account of individual's home environment	✓	✓	X	✓
Uses standardized tasks	X	X	X	✓
Assesses intimate activities (bathing, dressing, toileting)	✓	✓	✓	X
Assessed by someone familiar with individual's abilities	✓	✓	X	X
Not affected by cognitive difficulties	X	✓	✓	✓
Easily conducted in the home/community	✓	✓	X	X
Suitable for inpatient assessment	✓	X	✓	✓
Brief to administer	✓	✓	✓	X
Not affected by performance anxiety	✓	✓	✓	X

Note ✓: Characteristic usually present; X: Characteristic usually absent.

to the paucity of measures designed specifically for this population. It was designed for self completion by caregivers of people with dementia living in the community. Carers were involved both in the selection of activities for inclusion and in the design of rating levels for each activity. Items that were found to be insensitive, in that all the individuals with dementia either could or could not perform them, were removed from the scale.

This left 20 items assessing Basic ADL and IADL (food preparation, eating, drink preparation, drinking, dressing, personal hygiene, oral hygiene, bathing, toileting, transferring from bed or chair, mobility, orientation to time, orientation to place, communication, telephone use, housework/gardening, shopping, finances, games/hobbies and transport). Severity judgements range from independence (score 0 – no help required) through to dependence (score 3 – unable even with supervision), rated on a four-point scale. This produces a total score range of 0–60. In addition, caregivers can choose to score an item as not applicable, if the person with dementia never engaged in that activity when well. These not applicable items are scored 0.

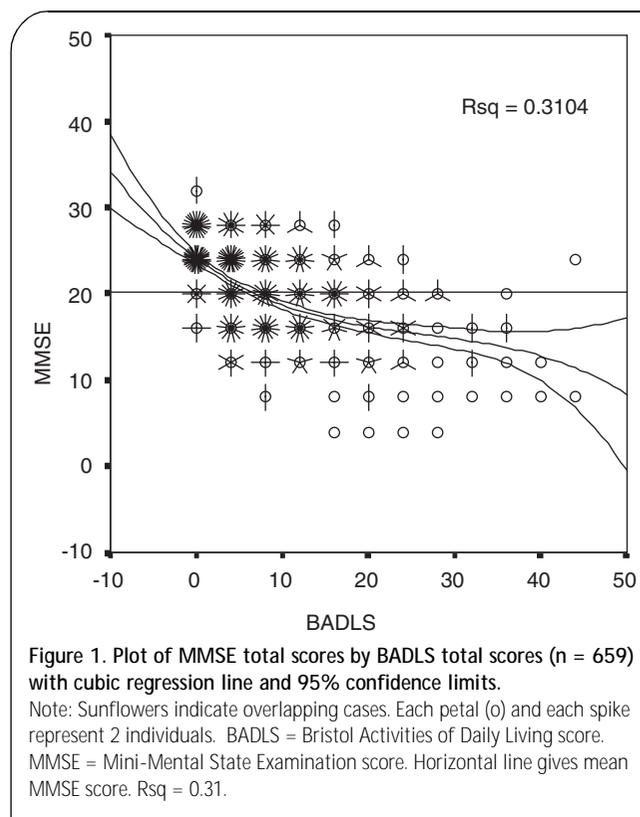
When compared with observed performance as rated by a nurse researcher in the participant's own home, the BADLS demonstrated good convergent validity ($r = 0.65$, 42% variance explained). This was an important finding given that other studies have shown only poor agreement between carer ratings and observed performance [34,35]. The BADLS correlated well with MMSE ($r = -0.67$, $p < 0.001$, 45% variance explained) and showed excellent test-retest reliability as measured both by correlation of scale totals ($r = 0.95$, $p < 0.001$, 89% variance explained) and by Cohen's kappa coefficients for each of the 20 items (seven items with fair or moderate kappa scores, 0.30–0.59; 13 with good or very good kappa scores, 0.62–0.94). Principle components analysis revealed four components with eigenvalues of greater than 1, which explained

65% of the variance. These components suggested that the BADLS has good construct validity since they appeared to reflect aspects of IADL (including telephone use, food preparation and housework), Orientation, Self Care or Basic ADL (including oral hygiene, bathing, dressing and toileting) and Mobility. Interestingly, very few caregivers used the 'not applicable' option, marking only 2.4% of possible responses in this way. Feedback from a number of users, however, suggests that some caregivers in other centers have found the 'not applicable' option confusing. In a modified version of the BADLS, the BADLS-revised (R), which is undergoing revalidation, the wording of this option has been changed to say 'never did it when they were well'. Since this was the guidance given to caregivers during the original validation study, however, it seems unlikely that this will cause any significant changes in the scale's characteristics.

In a subsequent study [36], the sensitivity to change of the original BADLS was established by comparison with NOSGER [27] – one of only very few scales available at the time – with evidence of sensitivity to change [37]. Change in BADLS scores showed the predicted relationship with change in cognition – a significant and modest correlation. Both scales were found to have good sensitivity and specificity in predicting change with cholinesterase treatment as measured by the clinician's global rating. For this study, a change score of ≤ -4 was defined as improvement on the BADLS and a change score of ≥ 2 as decline. Difference scores between -3 and 1 were defined as stable performance. Given that stability, in the context of an otherwise degenerative condition, can be viewed as a positive treatment outcome, BADLS produced a sensitivity of 74% and a specificity of 65% in detecting same or better *versus* worse performance by comparison with a clinician's global rating. The NOSGER produced sensitivity and specificity values of 31 and 46%, respectively.

Expert opinion

The BADLS has been in use in the Bristol Memory Disorders Clinic since May 18, 1998. Between this date and June 12, 2002, the BADLS was administered to the caregivers of 671 new patients referred to the clinic for assessment. Scores ranged from 0 to 44, with a mean of 8.7 (median 6, mode 0) and standard deviation (SD) of 8.4. The patients had a mean age of 73.0 years (SD 9.4, range 45–95) and were reporting a mean history of cognitive difficulties of 32.4 months (SD 28.3, range 3–180). Over half (358, 53.4%) were diagnosed with a dementia at this initial visit, 214 (31.9%) with cognitive impairment insufficient for a diagnosis of dementia, 77 (11.5%) with isolated memory difficulties and 22 (3.3%) as normal. The MMSE scores of those same individuals ranged from 3 to 30, with a mean of 20.1 (SD 5.3, median 21, mode 24). On the MMSE, 12 patients could not be tested but no such difficulty arose with the caregiver-rated measure. FIGURE 1 shows the relationship between MMSE (scored using serial 7s) and the BADLS for the remaining 659 patients. Whilst the BADLS and the MMSE are clearly related, the relationship is a modest one. This is reflected in the r square of 0.31 and the correlation between MMSE and BADLS given earlier in this article. Thus, the BADLS appears to measure aspects of functioning not tapped by the MMSE. Moreover, scales like the BADLS may offer educational opportunities for caregivers. We have found that caregivers find it easier to understand their relative's impairments if these are presented in terms of their effects on real-life activities rather than using abstract, often cognitive, language to



describe them. In particular, this offers the opportunity to educate caregivers as to the appropriate level of assistance required to promote independence in activities, which may result in ADL not being taken over by the caregiver.

The BADLS has been taken up widely in the UK and there is increasing interest from abroad. In a recent survey of 58 UK Memory Disorders Clinics, 26 of 45 (58%) reported the regular use of the BADLS [38]. In addition, the BADLS is being used in a large, simple, 'real-life' trial that aims to produce reliable evidence on the value of donepezil in routine clinical practice. In a very recent report of this trial, the BADLS was shown to decline approximately 1 point per 3 months over the first year in a linear fashion in untreated AD [39]. That the original scale has been used so widely is reassuring, but we should not be complacent. Although the idea for the original scale was developed by Gordon Wilcock, Consultant in Care of the Elderly only around 10 years ago, thinking about dementia and dementia care, as well as notions of disability and handicap has moved on since then. Even the BADLS may well find itself out of pace with these developments in the not too distant future. Before considering the next 5 years, we would like to reflect on some of those developments.

The BADLS was designed during a period when very early identification of dementia was not a priority. As public awareness has increased and as treatments have become available, there has been a shift towards earlier diagnosis. This shift necessarily requires tools that are more sensitive to early, subtle changes. This insensitivity to very subtle changes leads to ceiling effects in many scales, the BADLS included. Specifically, feedback from caregivers suggests that the level of dysfunction required to reach the first scoring point in the BADLS is too large in mild cognitive impairment or cases of very early dementia. Caregivers report that there is a definite change in ADL such that the individual is not entirely independent (score 0), but that these are not sufficient to warrant a score of 1 (indicating that some help is always required to perform the activity). Focus group work with caregivers reveals that, as a result, they choose the 0 (independent) option. As can be seen in FIGURE 1, for this sample of individuals seen at their first clinic visit, scores on the MMSE recorded for individuals with a BADLS score of 0 (independent) ranged from 14 to 30.

In response to this difficulty, in addition to changing the wording of the 'not applicable' option as already described, we have added an additional severity level (score 0.5) to all items: 'Clear change from previous standard, but not as bad as 'c'' (FIGURE 2). This wording derives from the words of caregivers themselves. The BADLS-R is currently being validated and is being compared with the original BADLS. Test-retest reliability data are also being collected.

However, although expedient, these revisions may not be the optimal response to the shift in the severity of disorder now being assessed with a view to diagnosis, nor to the problem of 'not applicable' responses. In an ideal world, we would begin again with the process of designing an ADL scale in order to develop items both sensitive to very early impairment

Figure 2. Example Bristol Activities of Daily Living – Revised item.

1. Food		Scoring
a. Selects and prepares food as required	[]	0
b. Clear change from previous standard, but not as bad as 'c'	[]	0.5
c. Able to prepare food if ingredients set out	[]	1
d. Can prepare food if prompted step by step	[]	2
e. Unable to prepare food even with prompting and supervision	[]	3
f. Never did it when they were well	[]	0

Note: In the Bristol Activities of Daily Living – Revised, an additional severity point scoring 0.5 (point b.) has been added using wording generated by caregivers themselves.

and appropriately scaled. We would also then be able to address more carefully the difficulty of distinguishing between 'not applicable: as never did it' and 'not applicable: as does not do it.' This speaks to a more general difficulty with regard to the tension between developing a brief scale, suitable for all individuals and easily administered, *versus* a longer, more individualized scale which might prove more informative, but less practicable. The BADLS, by necessity and design does not address all the types of ADL in which individuals engage and, therefore, will miss variance in the behavior of those people. These are all points to which we will return later in this paper when considering future directions.

Although early diagnosis is an important issue, perhaps the most important development, however, is a general change in the way we conceptualize impairment, disability and handicap. According to the WHO International Classification of Impairment, Disability and Handicap (ICIDH [40]), disability is defined as loss of or reduction in functional activity or capacity as a result of impairment. Handicap is the social disadvantage resulting from either impairment or disability. In the very recently published International Classification of Functioning, Disability and Health (ICF [41]), these terms and their relationships have been radically revised. The ICF proposes new concepts of 'activity' and 'participation'. Activity is defined as the execution of a task or activity by an individual, participation as involvement in life situations. Participation may be restricted by impairments, activities, health conditions and by contextual factors, such as features of the social or physical environment or the person themselves. In the new model, the interactions between concepts are flexible, reflecting the fact that one can have impairments without apparent limitations in capacity or *vice versa*. More importantly, perhaps, one can have impairments that do not limit participation in activities because of assistive technology or an environment that supports participation.

The ICF should be of relevance to the development of ADL assessments for two important and related reasons. Firstly, we need to be aware of the influence of secondary effects on the severity of an individual's condition. As Kitwood highlighted, low expectations from caregivers and professionals alike can lead to excess disability [42]. Secondly we may, therefore, not be measuring a person's actual capacity to perform a task, but rather the degree to which they are allowed, or are prepared to perform it: the distinction between 'can do' and 'do do.' In a recent community survey, Bootsma *et al.*, found that in community living adults (over 85 years) self-rating of their actual performance of basic ADL exceeded their self-reported competence to carry them out, but the opposite was true for IADL where their self-reported competence exceeded their self-reported actual performance [43]. Likewise, in the Framingham study, when self-reported ADL performance was compared with direct observation of the same activities, up to 7% discrepancies were observed in the cohort, with greater discrepancies being found in those with MMSE <24 [44].

The implications for the assessment of ADL in dementia are clear. If we are measuring what individuals do do, rather than what they can do, this difference will affect the sensitivity to change of such measures to treatment, as well as having implications for interventions themselves. Moreover, the ICF underscores the more general point that treatment can include not only changing neurotransmitters, but changing the environment in which an individual is placed so as to support their independence more fully. This might also include considering the perceptions of individuals and their family members and the effect this has on activity and participation. Thus, the ICF allows us to see individuals with dementia in a more positive way. This is not a mere philosophical nicety. Our tendency to classify and categorize individuals in terms of failure or dysfunction stresses their incompetence and may lead us to perceive only dependency [45,46]. By thinking about activities rather than disabilities and participation rather than handicap, we can begin to consider what might be the barriers to activity or participation. A positivist approach to the assessment of ADL seeks to find activities (at whatever level) that an individual with dementia can or could perform. This reversal of thinking allows us to believe that everyone, even the most severely affected person, is capable of some sort of activity. We are then challenged to find that activity and to determine a means of measuring it [47]. With measurement comes the possibility of assessing treatment outcomes, even late into the disorder. The relationship between environment and dependence has also been noted in other conditions. For example, the American Association on Mental Retardation have emphasized this relationship in their recently published criteria [48].

If it seems an insoluble proposition to develop ADL measures that capture the complexity of functioning, there are other new developments in thinking that may make it more achievable.

Consumer involvement

Over the last 10 years, there has been a growing shift of emphasis away from managing the individual as a passive recipient of care to seeing them as active players in the disease process [49–51]. We have begun to understand that individuals with dementia can communicate their experience, if only we can learn how to listen to what they have to ‘say’ [52]. This experience can be used to develop scales that measure activities or functions of real importance to individuals with dementia and their carers. In the early stages of these conditions, focus group or interview techniques can be used to explore appropriate areas for assessment [46,53]. In later stages, this may mean observational techniques that involve paying careful attention both to behavior and to what people have to say during their everyday lives, about their usual ADL, their daily frustrations and the aspects they would like to preserve or improve. One researcher in the Department of Psychology, University of Southampton, UK has been living with individuals with dementia and their caregivers for 3-day periods. She has observed that individuals appear to undertake different activities and different roles depending on whom they are with and the circumstances in which they are currently placed [Alison Carr, PERS. COMMUN.]. This level of attention to the experience of individuals and their caregivers should produce invaluable insights.

Additionally, although some ADL scales have been based on caregiver views (e.g., BADLS) many have been developed using the opinions only of professionals. None-the-less, caregivers probably have more to say about their experiences of living with an individual with dementia and about the changes which affect them the most. All of which need integrating into new scales.

Five year view

The combination of changes in classification of functioning and the growing impetus to involve consumers should lead to the development of functional scales in which caregivers and individuals with dementia will have largely determined the items on which they are to be assessed. It seems likely that this consumer involvement will result in measurement systems targeted, or indeed, mapped onto the stages of dementia (following naturalistic studies of longitudinal changes in ADL ability). A number of studies have explored rate of change of cognitive and functional decline in aging [54] and in AD [55]. Njegovan *et al.*, found that loss of functional abilities, such as ability to control finances was associated with group mean changes in cognitive performance [54]. Stern, studied rate of decline in basic ADL and IADL in 236 individuals with AD [55]. The rate of increase in instrumental ADL scores per 6-month interval attenuated as the scores increased, while that for basic ADL scores across intervals was constant. These findings suggest that the pattern of ADL decline, although correlated with cognitive performance, is varied between individuals. The challenge is to develop scales that can be sensitive to those individual differences and to establish which characteristics of the individual or their environment help one person retain independence in some ADL when others lose it, for a given level of cognitive impairment and in any given disease. Individuals with vascular dementia (VD), for example, show

greater difficulties with ADL early in the disease course than those with AD [46,56,57]. Therefore, there is a need to determine if current scales are equally suitable for VD and for other dementing conditions, such as diffuse Lewy body disease, frontal variant and fronto-temporal disorders.

Ideally, we would want a single scale sensitive to all stages of disease to allow reassessment over time. Unfortunately, this might be long and unwieldy. However, scales are beginning to be developed in which items are only addressed if an item, higher up in the developmental hierarchy, is responded to in the affirmative. For example, the Neuropsychiatric Inventory (NPI) has the option to pursue aspects of personality changes in more detail only if a caregiver endorses change in that general factor [58]. A similar technique could be applied to the assessment of ADL in dementia, expanding or contracting sections of a scale depending on the stage of the disorder an individual has reached. With falling prices of computer hardware, such as personal digital assistants and personal computers, it might even be possible to write a user-friendly software package to help administer and score such measures.

A variation on this theme might be to develop personalized or individualized ADL assessments which measure those aspects of behavior deemed relevant by a caregiver and/or the individual with dementia. Goal Attainment Scaling is an individualized technique that identifies four behaviors and markers for change in those behaviors, that caregivers and their relative wish to see changed through treatment [59]. An individualized ADL scale could take a similar form: a combination of a well-developed scale, sensitive to different stages of the disease, as outlined above, with the option to select only those behaviors deemed to be problematic for that individual. For example, caregivers might wish to focus on ten or so ADL, from a much larger list, on which the individual with dementia is most impaired. Finally, weighting of ADL items and severity statements may also be required to produce a sensitive scale that matches the developmental trajectory of different dementing conditions.

Key issues

- Many activities of daily living (ADL) scales were not originally designed for individuals with dementia.
- Consumers (individuals with dementia and their caregivers) need to be involved in the development of ADL measures.
- New scales are required that are sensitive to very early changes in ADL ability and to changes seen in severe dementia.
- Other dementing conditions, such as vascular dementia, diffuse Lewy body and fronto-temporal dementia may produce different patterns of change in ADL.
- Considerations of measuring ‘activity’ and ‘participation’ rather than ‘disability’ and ‘handicap’ need to underpin the development of new scales.
- Individualized ADL scales may prove sensitive to changes with treatment.

Information resources

WHO International Classification of Functioning, Disability and Health (ICF): www3.who.int/icf/icftemplate.cfm. ICF is a classification of health and health-related domains that describe body functions and structures, activities and participation. The domains are classified from body, individual and societal perspectives. Since an individual's functioning and disability occurs in a context, ICF also includes a list of environmental factors.

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Klein-Bell Activities of Daily Living Scale: www.hscer.washington.edu/hscer/pdfs/KleinBell.PDF. Contains a useful critique of previously developed scales followed by a new scale for Basic ADL and a sensitive breakdown of tasks required for independence in basic ADL. Unfortunately, the tasks were generated without the assistance of users.

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