Assessment of Activities of Daily Living, Self-Care, and Independence

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Accepted 22 June 2016

Abstract

Activities of daily living (ADL) comprise the basic actions that involve caring for one’s self and body, including personal care, mobility, and eating. In this review article, we (1) review useful clinical tools including a discussion on ways to approach ADL assessment across settings, (2) highlight relevant literature evaluating the relationship between cognitive functioning and ADLs, (3) discuss other biopsychosocial factors affecting ADL performance, (4) provide clinical recommendations for enhancing ADL capacity with an emphasis on self-care tasks (eating, grooming, dressing, bathing and toileting), and (5) identify interventions that treatment providers can implement to reduce the burden of ADL care.

Keywords: Assessment; Dementia; Disability/Handicaps; Everyday functioning

Activities of daily living (ADLs), often termed physical ADLs or basic ADLs, include the fundamental skills typically needed to manage basic physical needs, comprised the following areas: grooming/personal hygiene, dressing, toileting/continence, transferring/ambulating, and eating. These functional skills are mastered early in life and are relatively more preserved in light of declined cognitive functioning when compared to higher level tasks. Basic ADLs are generally categorized separately from Instrumental Activities of Daily Living (IADLs), which include more complex activities related to independent living in the community (e.g., managing finances and medications). IADL performance is sensitive to early cognitive decline, whereas physical functioning is often a significant driver of basic ADL ability (Boyle, Cohen, Paul, Moser, & Gordon, 2002; Cahn-Weiner et al., 2007). IADL impairment can often present in mild cognitive impairment and early dementia (Farias et al., 2013), whereas basic ADL declines are often not present until later dementia stages (Cahn-Weiner et al., 2007; West, McCue, & Golden, 2012).

We define capacity for ADLs more broadly than decision-making capacity in other domains explored elsewhere in this issue. Instead, we focus on the assessment to independently carry out basic ADLs and highlight the ability to engage in personal care as a key part of functional independence. In fact, ADL dependence is correlated with poorer quality of life (Broe et al., 1998; Millán-Calenti et al., 2010), increased health care costs, increased risk of mortality (Ramos, Simoes, & Albert, 2001; Scott, Macera, Cormman, & Sharpe, 1997) and institutionalization (Gaugler, Duval, Anderson, & Kane, 2007; Miller & Weissert, 2000). Once in a nursing facility, more dependent patients may be a greater drain on the available resources than those who are ADL-independent (Arling & Williams, 2003).

The ability to perform ADLs and IADLs is dependent upon cognitive (e.g., reasoning, planning), motor (e.g., balance, dexterity), and perceptual (including sensory) abilities. There is also the important distinction of the individual’s ability to complete the task (physical and/or cognitive ability) versus the ability to recognize that the task needs to be done without prompting (cognitive ability). In many settings, ADLs are directly assessed by occupational, physical or speech therapists, or by nurses and other members of the medical team to guide day-to-day care and/or as part of discharge planning. ADL capacity assessment often is requested during the middle or later stages of dementia but may also occur during the course of recovery for an acute event like a stroke. Referral for evaluation of ADL ability may include a question of cognitive,
emotional, or behavioral factors that can be interfering with functioning in these basic skills, and how these barriers may be overcome to enhance independence. In addition, DSM-5 diagnostic criteria for Major Neurocognitive Disorder specify that functional impairment with IADLs must be present for the diagnosis (American Psychiatric Association, 2013). ADL assessment may also occur as part of a broader capacity evaluation for independent living or guardianship.

The goal of this article is to provide clinicians with accessible and practical information on the assessment of a person’s ability to engage in ADLs, with or without assistance. We focus the paper on biopsychosocial factors that affect ADL care and clinical recommendations for enhancing capacity to engage in personal care. To place this in context, we first review models of disability in dementia, highlight relevant literature evaluating the relationship between neuropsychological functioning and ADLs, and identify commons ways of measuring ADLs. We also suggest interventions that treatment providers can implement to reduce the burden of care and enhance independence.

Cognitive Functioning and ADLs

The disability process was described by Verbrugge and Jette (1994) as beginning with an underlying pathology causing impairments that negatively impacts functioning, resulting in disability. This model considers the individual’s environmental context and coping process and other factors that can aid or worsen functioning. Barberger-Gateau, Fabrigoule, Amieva, Helmer, and Dartigues, (2002) applied this model in cases where dementia affects cognitive processes leading to functional impairments, which first impact IADLs like managing medications or finances and then basic ADLs. Consideration should be given to the personal and environmental factors that can alter the disability process in dementia, such as adequate social support or treatment for comorbid psychiatric problems.

ADLs comprised different types of skills requiring sequencing of action, conceptual knowledge, and manipulation needed to achieve the intended goal (Bienkiewicz, Brandi, Goldenberg, Hughes, & Hermsdörfer, 2014). Individuals with dementia vary significantly in ADL performance relative to MMSE score (Juva, Sulkava, Erkinjuntti, Yiloski, Valvanne, & Tilvis, 1994), thus stand-alone mental status examinations are of limited value in these types of evaluations. There are fewer neuropsychological studies conducted with individuals with ADL impairment than those with solely IADL impairment. This may be partly because individuals with ADL impairment are often more cognitively impaired overall and further along in the disease process (Barberger-Gateau et al., 2002; Perry & Hodges, 2000). Measures of ADL ability may also be less sensitive to changes in cognitive functioning, especially early on in the disability process (Koskas et al., 2014). Neuropsychological tests are often better at predicting IADL functioning compared to basic ADL functioning (Richardson, Nadler, & Malloy, 1995). Typically neuropsychological assessments alone are not in and of themselves sufficient to fully assess basic functional ability. Instead, an interdisciplinary approach including the use of specific ADL measures is recommended.

Global cognition and ADLs

In general, the ability to complete ADLs is typically well preserved in mild-to-moderate cognitive impairment. Jefferson and colleagues (2008) found no differences in ADL functioning between individuals with mild cognitive impairment and those with no cognitive impairment. However, as cognitive impairment worsens, the correlations between cognitive functioning and level of ADL dependence appear more consistent. For example, in a 52-month prospective study of functional decline in nursing home residents, more severe dementia was associated with poorer ADL functioning (Helvik, Engedal, Benth, & Selbæk, 2014). The Dementia Rating Scale (DRS) (Jurica, Leitten, & Mattis, 2001) has been found to have clinical utility in predicting basic ADL impairment, with a total score of 121 or less to the onset of significant ‘difficulties’ in ADL impairment (Fields et al., 2010).

There may be a hierarchy in functional decline of ADLs as cognition worsens. Katz theorized that the basic activities learned last in early development were the first to decline as cognition deteriorated (Katz & Akpom, 1976; Spector, Katz, Murphy, & Fulton, 1987). Njegov, Man-Son-Hing, Mitchell, and Molnar (2001) found that IADLs were lost at higher levels of cognitive functioning compared to ADLs although some overlap existed. Among the ADL categories measured, participants on average lost the ability to bathe independently before losing their ability dress, use the toilet, and transfer. Ability to groom and eat independently were the most well-preserved ADL tasks as cognition declined. In contrast, Fields et al (2010) found that when using a caregiver-report measure, problems in bathing and grooming appeared first, whereas eating was the last to be affected. Similarly, Giebel, Sutcliffe, and Challis (2015) found evidence for varying onset and rates of decline of each ADL in people with dementia. Bathing and dressing impairments were present in earlier stages, whereas toileting, ambulation, and feeding impairments were spared until the later stages. However, this assumption of hierarchy is not universally regarded, with some suggesting a more multidimensional approach to the assessment of ADLs.
ADL impairment has been shown to be predictive of future cognitive impairment and onset of dementia (Fauth et al., 2013), independent of current cognitive status or depression. Functional impairment can also cause cognitive decline to accelerate (Rajan, Hebert, Scherr, Mendes de Leon, & Evans, 2013). Among all ADLs, bathing impairment may have the highest risk of future institutionalization (Fong, Mitchell, & Koh, 2015).

**Specific areas of cognition and ADLs**

Many studies have been conducted on the relationship between attention, memory, executive functioning, and visuospatial functioning and ADLs. Attention has been found to be an important predictor of overall ADL scores in patients with Alzheimer’s disease (Hall, Vo, Johnson, Barber, & O’Bryant, 2011). Freilich and Hyer (2007) completed a factor analysis of the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) in relationship to ADL/IADL functioning. Poor performance on the Physical Self-Maintenance Scale correlated with impairment on the Attention and Immediate Memory Indices. With regard to specific ADLs, bathing impairment was associated with attention and total RBANS score. They suggested that attentional impairments that emerge later in the dementing process may be driving impairment in basic ADLs. It is not clear whether improving attention could improve ADL performance.

Some studies have demonstrated a relationship between memory and ADL functioning. For example, Jefferson and colleagues (2006) assessed patients with probable vascular dementia on cognitive functioning (using the DRS) and ADLs (instrumental and basic ADLs using informant-based measures) at baseline and 1 year later. Using logistic regression, they found that changes in memory scores (measured by the DRS Memory subscales) significantly predicted declines in basic ADLs. In another study, both immediate and delayed memory predicted deficits in dressing ability (Farias, Harrell, Neumann, & Houtz, 2002).

As compared to domains of memory and attention, results of studies evaluating the relationship between ADLs and executive functioning are more convincing (Lewis & Miller, 2007). Difficulties in executive functioning have been shown to predict both ADL and IADL impairment in women and men with mild Alzheimer’s disease (Hall et al., 2011) and compared to women without cognitive impairment, those with executive functioning impairment (demonstrated by Trails B) had significantly worse ADL functioning over the course of 6 years (Johnson, Lui, & Yaffe, 2007). Trail B appeared more sensitive to ADL disability than the global cognitive measure (MMSE). Boyle and colleagues (2003) found that executive cognitive dysfunction (measured by the DRS Initiation/Perseveration subscale) was associated with ADL performance (measured by the Lawton & Brody ADL questionnaire) in those with mild-to-moderate Alzheimer’s disease. However, they highlighted that the magnitude of this effect was greater for IADLs. In more recent work, a meta-analysis found a moderate association between executive functioning and independence in ADLs in individuals with Alzheimer’s disease (Martyr & Clare, 2012). However, Cahn-Weiner, Boyle, and Malloy (2002) found no relationship between caregiver report of basic ADLs on the Physical Self-Maintenance Scale and well-known executive function tests including Trail B, Wisconsin Card Sorting Test, and the Controlled Oral Word Association Test, whereas these measures correlated with IADL performance. The authors suggested that IADL and ADL functioning may be composed of different underlying performance factors.

Given that some ADLs require the use of tools in a dynamic environment, visuospatial skills have been found to play a role in basic ADL functioning (Richardson et al., 1995). Perry and Hodges (2000) analyzed the relationship between cognitive and functional performance in patients with early Alzheimer’s disease. The strongest relationship was found between self-care measures (ability to dress, bathe, eat meals, and groom independently) and visuospatial functioning, which was measured using subtests from the Visual Object and Space Perception Test (Warrington & James, 1991). The next strongest relationship was found between self-care measures and semantic memory (using three different tests). They inferred from these findings that a combination of parietal and temporal dysfunction affects the ability to competently use objects, and therefore plays a significant role in the decline of ADL capability. Freilich and Hyer (2007) also found that grooming impairment was correlated with the visuospatial index and total RBANS score.

Assessing apraxia can be particularly important in cases of recent stroke. Apraxia is typically classified into three types: ideational (inability to plan and execute complex gestures, such as the use previously familiar tools), ideomotor (inability to imitate hand gestures), and limb-kinetic (difficulty executing precise movements) (Goldenberg, 2003). Apraxia may most directly affect grooming, bathing, and toileting tasks, while relatively sparing mobility and dressing (Hanna-Pladdy, Heilman, & Foundas, 2003). Apraxia as it relates to ADL functioning may be assessed using a combination of both praxis tests and ADL performance-based measures, as self-report is not sufficient and only using ADL instruments like the Barthel may not capture the extent of apraxia (Donkervoort, Dekker, & Deelman, 2002).
ADL Assessment Approaches and Tools

A full neuropsychological evaluation is generally not be necessary or practical in many cases assessing basic ADLs, particularly if the referral questions centers on the types of current ADL impairment. If the person has a known dementia diagnosis and is severely impaired across ADLs, more in-depth cognitive testing may not be indicated. In these cases, using one of the following ADL tools, along with observations and collateral information from caregivers may suffice. Other disciplines may perform ADL assessment and document it in the medical records, so it can be useful to be aware of which measures are commonly by other providers. Sometimes, the referral question may center on why the ADL impairment is present and whether it can be remediated. In these cases, performing a more thorough cognitive evaluation (including direct ADL measures alongside cognitive and motor tests) may help to clarify the neuropsychological impairment driving ADL impairment.

Several types of approaches have been used to quantify level of independence in ADLs. ADLs may be measured by self-report, proxy/caregiver/informant report, and/or direct observation. These tools obtain a general sense of the level of assistance needed and the type of setting that is most appropriate for the patient. Self-report measures are convenient to administer and are frequently used when direct observation is not possible or when individuals are relatively cognitively intact. However, they may be less valid when individuals have poor insight into their functional impairments (Desai, Grossberg, & Sheth, 2004, Jekel et al., 2015). Performance-based measures can provide objective data about ADL functioning but generally require more training to administer as compared with self or informant reports.

Informant-based ratings are commonly completed by caregivers who know the patient well, but how also may be biased by their own burden in caring for the individual or by over or underestimating the patient’s true functioning. Caregiver report can thus be useful to include in evaluation of ADLs although may not be entirely free of bias. Miller and colleagues (2013) found that self-report measures of ADLs can be compromised in those with more severe cognitive impairment, and that report by an informal caregiver may be a more accurate assessment of functioning in a community sample. However, Cotter, Burgio, Stevens, Roth, and Gitlin (2002) compared caregiver completion of the Functional Independence Measure (FIM) with video recording of the caregivers assisting with ADLs and found that although caregivers’ report of the type of assistance provided was accurate, they overestimated the amount of time they spent assisting the care recipient with the ADL task. Furthermore, they suggest caregivers may be used to doing more for the care recipient than is necessary, so may underestimate the functional status of the care recipient.

A combination of self-report and performance-based measures of ADL performance may be the best way to fully capture the picture of disability for a given individual (Bravell, Zarit, & Johansson, 2011). Both the objective performance measure of the task derived from a performance-based measure and the individual’s subjective appraisal of how they are doing reflected in a self-report can be useful in contextualizing ADL capacity (Angel & Frisco, 2001).

Some measures group ADLs together with IADLs (e.g., the Direct Assessment of Functional Status, (Loewenstein, Amigo, & Duara, 1989), a performance-based measure that includes basic skills like feeding dressing and grooming and higher level tasks like writing out a check and using a telephone), while other measures distinguish between the two (e.g., the Physical Self-Maintenance Scale [PSMS] and IADL scale) (Lawton & Brody, 1969). We review several of the most commonly used clinical measures here. Additional scales and measures can be found in Moore, Palmer, Patterson, & Jeste, 2007.

Although assessing basic ADLs may appear relatively straightforward, ADL measurements and scales can vary significantly. Measures differ in their ability to rate level of dependence and the type of assistance needed for each activity. The Katz Index of independence in ADLs (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) is one of the most commonly used tools to assess basic ADLs (bathing, dressing, toileting transferring, continence, and feeding). Clinicians rate individuals as either fully independent (no supervision, direction, or personal assistance needed) or dependent (needing supervision, direction, personal assistance, or total care) across the six skills, with a maximum score of six points indicating fully independent, four points moderately impaired, and two points severely impaired. This measure was originally created to assess the physical functioning among those who were in rehabilitation. The PSMS (Lawton & Brody 1969) is an informant-report measure. Each of six ADLs (toilet, feeding, dressing, grooming, ambulation, and bathing) is rated as dependent or independent and has more descriptors than the Katz measure. Another test, the PSMS, is typically paired with an IADL measure also developed by the authors, which may help to reduce potential age bias as compared with Katz (LaPlante, 2010). The Older Americans Resources and Services (OARS) is a self-report questionnaire that consists of 14 questions related to ADL and IADL levels of independence. ADLs measured within this questionnaire included feeding, dressing, grooming, walking, transferring (in and out of bed), bathing or showering, and going to the bathroom. They are coded from 0 (completely unable) to 2 (without help), and an overall ADL rating is derived to characterize functioning from “Completely Impaired” to “Excellent” (George & Fillenbaum, 1985).

In contrast to the Katz, which is a good fit in long-term care where patients’ disability is typically more severe and stable, the Barthel ADL Index (Mahoney & Barthel, 1965) may be better suited to more acute settings (Hartigan, 2007). The Barthel
Covers eight domains: feeding, bathing, grooming, dressing, bowel, bladder, toilet, transfers, mobility, and stairs. Clinicians rate patients on the ability to perform these ADLs in a real-world setting over the prior 24–48 hr, based on self-report, collateral information, and direct observation. Performance on these domains is rated by level of assistance needed, with each task yielding a maximum score of 100 points, with independence in transferring and stairs weighted more heavily than other ADLs. One of its strengths compared with the Katz is that it may offer a more nuanced picture of disability and be able to detect more subtle changes in functioning (Hartigan, 2007; Roedl, Wilson, & Fine, 2015). The FIM (Keith, Granger, Hamilton, & Sherwin, 1987) is more comprehensive than the Katz or the Barthel, as in addition to basic ADLs, it includes domains of social cognition and communication that are not present in those measures. It is typically used by a clinician but has found to be valid as a self-report instrument with some populations (Grey & Kennedy, 1993).

Compared with self or informant-report, performance-based measures such as Performance ADL Test (PAT) (Weening-Dijkstra, Kamsma, & Van Heuvelen, 2011) and the Erlangen Test of Activities of Daily Living (E-ADL-Test, Graessel et al., 2009) provide a more objective evaluation of the person’s true abilities measured in a way that is quantifiable and repeatable. For example, the PAT includes measures of fine and gross motor control, and assesses both basic and instrumental ADL tasks, so may be able to detect change over time in a way that self-report cannot. The E-ADL-Test consists of five simple activities related to eating and self-care, each scored on a 6-point scale of accuracy. Other instruments such as the Texas Functional Living Scale (Cullum et al., 2001) and Independent Living Scales (Loeb, 1996) also include performance-based measures of daily activities and can address self-care more broadly (e.g., identifying the benefits of regular personal hygiene). However, they mainly evaluate IADLs rather than ADL.

Other Factors Associated with ADLs

Comorbid psychiatric issues can affect the ability to carry out ADLs. When hallucinations and delusions are present in dementia, individuals have greater ADL disability (Cohen-Mansfield, Golander, Ben-Israel, & Garfinkel, 2011, Rapoport et al., 2001). Differential diagnoses or symptoms that may be contributing to ADL impairment include depression and apathy (Boyle et al., 2003; Mendes de Leon & Rajan, 2014). Apathy may account for 15% of the variance in basic ADLs of patients with mild-to-moderate Alzheimer’s disease, after accounting for cognitive functioning (Boyle et al., 2003). Depression may be a particularly harmful risk factor for ADL impairment earlier in the process of cognitive decline, though treatment can yield functional gains (Lenze et al., 2005; Nyunt, Lim, Yap, & Ng, 2012; Rist, Capistrant, Wu, Marden, & Glymour, 2014). Rist et al. (2014) suggests a model in which both cognition and behavioral risk factors such as depression mutually reinforce each other in driving the progression of disability. Functional disability has also been found to be predictive of depressive symptoms. Mobility, transferring, and dressing impairments have a particularly strong association with depression (Boström et al., 2014; Meltzer et al., 2012), possibly due to the relatively higher frequency with which these activities occur for the person with dementia as compared with other ADLs. Depression and disability can worsen after ADL assistance is initiated, perhaps due to learned helplessness on the part of the care recipient or loss of regular activity that could mitigate further disability (Lin & Wu, 2011).

Usual aspects of a thorough clinical evaluation with older adults are also germane in ADL assessment. Sensory deficits may interfere with completion of ADLs, and many older adults have losses in more than one sensory domain, compounding the impact on functioning (Brennan, Horowitz & Sue, 2005). Pain may be contributing to ADL disability and problems with mobility (Eggermont et al., 2014). Pain can be difficult to detect in older adults with dementia (Apinis, Tousignant, Arcand, & Tousignant-Laflamme, 2014), especially if the person is unable to communicate well. Self-report is the gold-standard for pain assessment but when it cannot be reliably utilized, Hadjistavropoulos et al. (2014) suggest alternate means for an evaluation including the use of a standardized observational measure of pain behaviors like facial grimacing, changes in social interaction or daily routines, and collateral report. Fear of choking or falling may also be interfering with a person’s willingness to complete some ADLs such as eating. Coordinating behavioral interventions with rehabilitation staff may help to address these fears and instill confidence in the individual to perform the task.

An important aspect of assessment is determining whether the individual is simply refusing to complete an ADL and if so, their motivation for doing so. Often this may be construed as “resistance to care,” and may have negative ramifications such as being prescribed antipsychotics when behavioral interventions may be more effective. Refusal of care can be emotionally draining for caregivers and nursing staff. People with dementia may not understand why they are being confronted and may not be able to verbalize their reasons for refusing care.

Self-neglect may also affect an older person’s ability to attend to and carry out daily self-care tasks. Older adults who self-neglect may have inadequate nutrition and hydration, poor personal hygiene, or be unable to care for their basic personal needs. Self-neglect has been found to be associated with overall cognitive decline and executive dysfunction specifically, but
these are modest correlations (Dong et al., 2010). The Self-Neglect Severity Scale, (Kelly, Dyer, Pavlik, Doody, & Jogerst, 2008) is a 37-item screening tool for self-neglect. This instrument can be administered in the home environment and covers two domains assessed by clinician observation: hygiene (e.g., care of self and clothing) and environment (e.g., upkeep of home), and a third domain, impaired functioning, that includes a brief clock-drawing test, record review, and examination of the patient. The Kohlman Evaluation of Living Skills (Kohlman-Thomson, 1992), an occupational therapy tool combining self-report, clinical observation and performance tasks, may also be useful in evaluating safety risks due to self-neglect, and as part of an independent living capacity evaluation (Burnett, Dyer, & Naik, 2009; Pickens, Naik, Burnett, Kelly, Gleason, & Dyer, 2007).

A common fear among older adults is becoming a burden on others, especially loved ones. Changes in ADLs may predict further cognitive impairment that has important implications for future care planning. Increasing dependency may signal the need for a care conversation between providers, the patient, and their family or surrogate to clarify the patient’s desires, should they be unable to provide for their basic needs. Optimally, documents such as a medical power of attorney or advance directive would be completed well before the person could not meaningfully make their wishes known.

Caregiver burden is critical to assess, as it can be predictive of costly institutionalization. The physical and mental burden of providing ADL care can be heavy for informal caregivers (Shen, Feld, Dunkle, Schroeper, & Lehning, 2015; Vaingankar et al., 2016). For example, caregiving often interferes with time that could be spent on self-care and social activities (Savundranayagam, Montgomery, & Kosloski, 2010). When they begin assisting their spouses with ADLs, men and particularly women may be at greater risk of depression and physical health problems (Black et al., 2013; Covinsky et al., 2003; Dunkle et al., 2014). Thus, this time point may be crucial in providing coping strategies and other support.

Clinical Recommendations

Clinicians should consider modifiable risk factors that may reverse ADL decline or enhance current functioning, including depression, pain, exercise, and other health behaviors. In a large longitudinal study of adults 50 and older, Rist et al. (2014) examined the effects of modifiable risk factors on ADL impairment (eating, dressing, bathing, transferring in and out of bed, and ambulating across a room) in individuals with varying levels of cognitive impairment (from low to high probability of having dementia at the time of the study). Smoking increased risk of any ADL impairment regardless of cognitive functioning but had a stronger negative impact in those with greater likelihood of cognitive impairment. Researchers also found that those who were already moderate alcohol drinkers (1–2) drinks per day had less risk of ADL decline than either those with heavier alcohol use or those who did not drink at all. In the moderate alcohol group, cutting down to fewer drinks or eliminating alcohol entirely was unlikely to change the functional outcome for basic ADLs. In a later study by the same authors, neither smoking nor drinking effects were found when examining IADL risk impairment across the same range of cognitive functioning, suggesting these specific modifiable risk factors may play less of a role earlier on in the process of functional decline. Alternately, it may be that health behaviors like smoking may have greater detrimental to the largely physical abilities involved in ADL functioning, as compared with more cognitively demanding IADL ability (Rist, Marden, Capistrant, Wu, & Glymour, 2015). Social engagement may also help to both stave off the onset and slow the growth of ADL disability, so older adults should be encouraged to begin or continue participating in meaningful activities outside the home (e.g., attending religious services or volunteering) (Mendes de Leon & Rajan, 2014).

Simple changes can make completion of ADLs easier for older adults to perform independently. For example, for those with moderate-to-severe dementia, using finger foods or foods that are soft and easier to chew may help, as well as considering other ways to break down eating tasks into less complex steps (Liu et al., 2015). Building postural and mobility skills can help improve toileting independence (Talley et al., 2014). Shirts or slacks with Velcro attachments can be easier for individuals with arthritis put on or remove. Rehabilitation therapists and dieticians are key partners in helping adapt these skills to promote independence.

Phyllis was an 83-year-old woman residing in a long term care facility. She was bed bound and frail, with a faint voice that was a result of her Chronic Obstructive Pulmonary Disease. When initially admitted, she was able to feed herself independently. However, after a few weeks in the facility, she began insisting that she could not eat on her own and that she needed someone to help feed her. Staff were split on whether to assist in her feeding or to continue encouraging her to eat on her own. Was she declining cognitively or physically? Was she in need of more attention? Depressed? A referral to the psychologist was made. Phyllis told the psychologist that she takes a long time to eat and was concerned that her tray would be taken before she could finish her meal. It would also become cold after a while which was unappetizing for her. She assumed there was no other way around this and therefore did not figure it was worth telling anyone. Once the team understood her concerns, they worked with Phyllis to develop a personalized care plan, which included telling her that she could keep her tray as long as needed, reheating her food, and having staff assist her if needed. Phyllis wanted to be able to eat on her own, but also wanted the option to be helped if she was feeling tired. Staff agreed to ask Phyllis her preference before each meal.
Unique environmental and interpersonal factors can contribute to impairments in specific self-care ADLs. In long-term care settings, misguided approaches and institutional pressures can interfere with feeding independence, by emphasizing caloric intake, completion of a meal, and prevention of weight loss, rather than enjoyment of meals and ensuring that eating is a pleasurable experience (Liu, Galik, Nahm, Boltz, & Resnick, 2015). Toileting impairment may be due to a combination of incontinence, poor mobility, and level of comorbid ADL disability, particularly bathing and dressing impairment (Talley, Wyman, Bronas, Olson-Kellogg, McCarthy, & Zhao, 2014). Moreover, bathing difficulties can be driven by the approach of the caregiver, the bathing environment, and the individual needs of the care recipient (e.g., sensory impairment) (Cohen-Mansfield & Parpura-Gill, 2007).

Evidence-based approaches can be implemented to reduce challenging behaviors in dementia, which in turn may help decrease caregiver burden. In the home or institutional settings, functional outcomes may be improved with evidence-based interventions support such as Resources for Enhancing Alzheimer’s Caregiver Health (REACH-II) (Elliott, Burgio, & DeCoster, 2010) or Staff Training in Assisted Living Residences (STAR-VA: Karel, Teri, McConnell, Visnic & Karlin, 2016). REACH-II is a 6-month intervention for caregivers combining in-home sessions and telephone contacts to deliver individualized dementia caregiver support. Among positive outcomes were improvements in caregiver well-being, (likely mediated by improvement in caregiver depression) as well as improvements in the perceived nuisance of assisting the care recipient with ADLs. In institutional settings, partnering with direct care staff to develop individualized care plans can produce positive results for both patients and staff. STAR-VA (Karel et al., 2016) was initially an assisted living staff intervention adapted to VA Community Living Centers (long-term care facilities). Individualized behavior plans are developed to address psychological distress in residents with behavioral problems in dementia, including refusal of ADL care. This intervention has shown strong outcomes in reducing the frequency and severity of depression, agitation, and challenging behaviors and is being adopted at VA sites nationwide.

Evidence-based approaches to helping persons with dementia and their caregivers with specific ADLs are also being developed. To alleviate family caregiver burden and discord around dressing, Mahoney, Burleson, Lozano, Ravishankar, and Mahoney (2015) have begun testing a technological dressing intervention, DRESS (Development of a Responsive Emotive Sensing System). They developed this system and found it to be feasible for dementia caregivers by incorporating wearable technology and a smart dresser that has been modified to provide visual cues and feedback to people with dementia. The system senses the level of frustration the person with dementia is feeling as they engage with the task. Essentially, the caregiver is removed from the interaction unless the person becomes very upset, with the goal to alleviate power struggles between caregivers and care recipients.

In later stages of dementia, bathing and showering may be quite frightening especially in unfamiliar surroundings. At home, older adults and/or their family caregivers may find providing bathing care uncomfortable to receive or provide. Utilizing a paid home health aide to provide personal care may alleviate some of these concerns. Reasonable modifications at home or in long-term care settings may include in-bed baths or washing without water (e.g., sponge-bathing), which may insure that all areas of the body are routinely cleaned with less disruption to care recipients (van Achterberg et al., 2015). Person-centered bathing approaches like the Bathing without a Battle intervention developed by Mahoney, Burleson, Lozano, Ravishankar, and Mahoney (2015) have begun testing a technological dressing intervention, DRESS (Development of a Responsive Emotive Sensing System). They developed this system and found it to be feasible for dementia caregivers by incorporating wearable technology and a smart dresser that has been modified to provide visual cues and feedback to people with dementia. The system senses the level of frustration the person with dementia is feeling as they engage with the task. Essentially, the caregiver is removed from the interaction unless the person becomes very upset, with the goal to alleviate power struggles between caregivers and care recipients. In this safety-focused intervention, care providers were coached to recognize and respond to signs of discomfort or distress during the bathing process. This intervention resulted in fewer behavior problems (e.g., yelling) while also shortening bath times.

Conclusions

Unlike with other types of capacity, neuropsychological tests may have less predictive validity for ADL assessment. There is some evidence that changes in attention, executive functioning, visuospatial tasks, and memory can affect ADLs, generally in later stages of dementia. Using self-report, caregiver report, and/or performance-based measures of ADL functioning can be clinically useful, particularly in interdisciplinary settings. It is important for clinicians to attend to factors that drive or worsen ADL impairment, particularly those that may improve with treatment such as depression, resistance to care, and pain. ADL impairment can have significant ramifications for patients and their caregivers, as it can lead to caregiver burnout and institutionalization. Patient-centered approaches to enhancing independence in self-care activities can improve quality of life for patients and help to alleviate caregiver burden.

Conflict of Interest

None declared.
Acknowledgments

This material is the result of work supported with resources and the use of facilities at the VA Boston Healthcare System.

References


