Assessing capacity in suspected cases of self-neglect

AANAND D. NAIK, MD,
Research Investigator, Houston Center for Quality of Care & Utilization Studies, Michael E. DeBakey VA Medical Center; and Geriatrics Program, Harris County Hospital District, Baylor College of Medicine, Houston, Tex.

JAMES M. LAI, MD,
Postdoctoral Fellow, Section of Geriatric Medicine, Department of Internal Medicine, Yale University School of Medicine, New Haven, Conn.

MARK E. KUNIK, MD, MPH, and
Associate Director, Houston Center for Quality of Care & Utilization Studies; and Associate Director, Research Training, VA South Central Mental Illness Research, Education, & Clinical Center (MIRECC). He is Professor, Menninger Department of Psychiatry and Behavioral Sciences, Baylor College of Medicine, Houston, Tex.

CARMEL B. DYER, MD
Director, Division of Geriatric Medicine, Department of Internal Medicine, The University of Texas Health Science Center at Houston; and Co-Director, Texas Elder Abuse and Mistreatment Institute, Houston, Tex.

Abstract

Self-neglect is a serious and burgeoning public health challenge representing the most common problem faced by Adult Protective Services agencies. Among older adults who are vulnerable to self-neglect, the capacity to make decisions may remain intact. However, the capacity to identify and extract oneself from harmful situations, circumstances, or relationships may be diminished. A key ethical and clinical branch point in identifying older adults at risk for self-neglect involves determining whether the individual can both make and implement decisions regarding personal needs, health, and safety. The Articulate Demonstrate method is a practical and efficient way to screen capacity in the setting of suspected self-neglect. Once self-neglect has been identified, common clinical interventions can be targeted to the diagnosed deficits that foster vulnerability to neglect in older adults.

Keywords

elder abuse and neglect; self-neglect; capacity; geriatric assessment

Case presentation

Mrs M is a 78-year-old woman who lives alone at home. She has become immobile because of degenerative arthropathy and has developed pressure ulcers. A concerned neighbor contacts a geriatrics house-call team to evaluate the patient at home. The team finds superficial pressure ulcers over both ischial bones and arranges for a home health agency to provide wound care. Over the next several weeks, Mrs M fails to follow the agreed management plan. The wounds progress despite home nursing visits and extensive patient education. Concerned about the patient’s decision-making and executive functional abilities, the geriatrician performs a clinical evaluation to assess Mrs M’s capacity to manage her self-care needs. On examination, she has refined social graces and expresses clear preferences. She adamantly states that she can take
care of her wounds and prefers to be left at home rather than transferred to a hospital or skilled
nursing facility. Her Mini-Mental State Examination and Geriatric Depression Scale scores are
in the normal range. The geriatrician believes that she demonstrates adequate capacity to make
a decision about how to manage the ulcers, yet still remains concerned that her condition will
continue to decline. At a follow-up visit 2 weeks later, the wounds are contaminated with
maggots and feces. The geriatrician successfully petitions the court for an emergency removal
of Mrs M and admits her to the local hospital.

Clinically, adults who self-neglect either reject or cannot access necessary support, including
social, medical, and financial services. They often have advanced undiagnosed and untreated
medical and psychiatric conditions including dementia and depression. They manifest poor
hygiene and live in squalor; at times, their homes are falling down around them. The National
Committee for the Prevention of Elder Abuse and the National Adult Protective Services
Association define self-neglect as “an adult’s inability, due to physical or mental impairment
or diminished capacity, to perform essential self-care tasks including (a) obtaining essential
food, clothing, shelter, and medical care; (b) obtaining goods and services necessary to maintain
physical health, mental health, or general safety; and/or (c) managing one’s own financial
affairs.”

Self-neglect is a serious and burgeoning public health challenge representing the most common
problem faced by Adult Protective Services (APS) agencies in the United States. The 2004
survey on the abuse of adults aged 60 and older indicates that the APS received almost 85,000
reports of self-neglect in this older population, and this number represented just 21 states able
to provide specific information on self-neglect by age group. Self-neglect also accounted for
37% of substantiated reports of elder abuse, the largest percentage for any elder abuse category.

Self-neglect, like other geriatric syndromes, is associated with significant morbidity and is an
independent risk factor for death. The established risk factors for self-neglect include old age,
cognitive impairment, depression, delirium, functional and social dependence, history of social
isolation, alcohol and substance abuse, and presence of a personality disorder.

Capacity for self-care and self-protection

Among adults who are vulnerable to self-neglect, the capacity to make some decisions may
remain intact. However, the capacity to identify and extract oneself from harmful situations,
circumstances, or relationships may be diminished. A key ethical and clinical branch point in
identifying self-neglect involves determining whether the individual can both make and
implement decisions regarding personal needs, health, and safety (ie, does the patient possess
the capacity for self-care and self-protection [SC&P]?).

Traditionally, legal declarations of competence or decision-making capacity are treated as a
threshold phenomenon: either one has capacity, or one does not. Access to treatment, or even
legal rights, can be taken away if an individual lacks competence. Capacity for SC&P, however,
should be viewed along a clinical gradient rather than as a threshold phenomenon. This
distinction is important to avoid unnecessary infringements of patients’ rights and
simultaneously adding a huge physical and financial burden on health- and social-services
providers. If the impairments are too severe, the interventions fail to ameliorate them, or the elder refuses to implement the intervention, then legal steps must be taken to redress the persistent deficits in capacity for SC&P.

**Dimensions of capacity**

To clarify the ethical and conceptual definition of capacity for SC&P, these conceptual dimensions should be considered: the process of making decisions for oneself or extending that power to another individual when it is impaired (decisional capacity); and the process of putting one’s decision into effect either alone or by delegating those responsibilities to another, more physically able individual (executive capacity). Both dimensions should be assessed when evaluating the capacity for SC&P.

Decisional capacity is defined by 4 criteria. Elders must understand the basic facts surrounding a decision; appreciate the personal impact of the decision, including one’s capabilities and limitations; have a reasoning process for comparing the options and predicting the consequences of alternative choices; and be able to make a choice. Alternatively, executive capacity is the ability to execute one’s decisions. Execution of one’s decisions is predicated on having a predetermined plan, adapting the plan in response to changing or unexpected circumstances, and delegating these responsibilities to appropriate surrogates when one is physically unable to carry out the plan.

The capacity for SC&P, however, can be complex. Individuals, such as the patient described in the case presentation, may retain some or all of their ability to make medical decisions about wound care management but lack the ability to safely and effectively care for their wounds outside the hospital. From a clinical perspective, it may be difficult (and often impractical) to determine whether impairments are purely decisional or executive in nature. A more pragmatic approach is to focus on the functional domains that are affected by potential declines in capacity.

**Domains of self-care and self-protection**

Clinicians are often asked to assess vulnerable older adults who demonstrate a decline in self-care behavior, live in unsafe settings, or have frequent exacerbations of treatable chronic conditions. A key component of this evaluation is identifying how the potential impairments manifest within the context of functional domains related to safe and independent living. These domains are broadly divided into 5 categories: personal needs and hygiene, condition of home environment, activities for independent living, medical self-care, and financial affairs and estate. Table 1 describes these domains and provides examples of screening questions to assess decisional and executive dimensions of capacity within the context of each of these domains.

Personal needs and hygiene include the basic elements of self-care and self-protection; for example, activities of daily living (ADL) such as bathing, dressing, toileting, and feeding. Transferring and ambulation within the home are other aspects of personal needs and hygiene. Condition of the home environment includes routine maintenance, appropriate repairs, and the physical structure of the living environment. Although respect for cultural standards and lifestyle choices is imperative, individuals living in environments that threaten their health or safety warrant a clinical evaluation. Poorly maintained home environments can produce significant risks that include toxins from pet and animal waste, accidents related to fire and electrical hazards, exposure to extremes in weather, and illnesses arising from uncollected garbage and sewage.

Clinicians may evaluate patients’ capacity to make decisions in this domain by examining whether patients appreciate their personal and environmental needs and the health and safety
risks arising from their limitations and can articulate a process of accomplishing the tasks necessary to fulfill personal needs. Executive capacity is demonstrated through attempts to adequately maintain personal needs and the home environment. Patients physically unable to perform these necessary tasks may still retain capacity by identifying appropriate social and caregiver supports to fulfill these needs when they themselves cannot.

The other 3 domains include many traditional instrumental activities of daily living (IADL). Management of medical self-care and financial affairs is differentiated from the other activities for independent living because of the increased opportunities for presentation to social- and health-services providers with declines in these 2 domains. Activities for independent living include shopping and meal preparation, laundry and cleaning, using the telephone, and transportation. Medical self-care can include routine activities such as managing a medication regimen, self-monitoring of blood pressure or glucose, and wound care. This domain also includes assessments of the way an individual handles acute problems (eg, severe chest pain) or practical obstacles (eg, running out of medications). Capacity with everyday financial affairs involves having an understanding of the importance and role of money, an appreciation of one’s financial situation, and a reasoning process for making financial decisions and reacting to new or unexpected circumstances (eg, exploitation schemes), as well as managing one’s assets or making routine transactions.

**Practical approach to capacity assessment**

Clinicians should initiate a capacity assessment whenever they encounter a patient who is vulnerable to self-neglect or one whom they suspect of being vulnerable to neglect by others (see risk factors described previously). Table 2 describes many common presenting signs and symptoms of self-neglect. Within this context, the Articulate Demonstrate method is practical and efficient for evaluating capacity for SC&P when an at-risk older adult presents with one or more signs of self-neglect (see Figure 1, page 29). Clinicians can initiate this method in the office setting using an individualized approach that targets 1 or more of the 5 specific domains of SC&P or a standardized approach that uses validated instruments for assessing functional status, decision-making capacity, and cognitive ability. The Articulate Demonstrate method is a 2-step method for evaluating the 2 dimensions of capacity (decisonal and executive). The Articulate step (Figure 1, left column) consists of office-based assessments to measure the capacity to make decisions. In contrast, the Demonstrate step (Figure 1, right column) consists of proxy reports and in-home or clinical evaluations of the vulnerable elder’s capacity to perform the domains of SC&P. The intent of the 2-step method is to provide a conceptual guide rather than a stepwise procedure algorithm. A clinician could start with standardized assessments before individualized ones. Proxy reports and assessments of executive capacities may precede an evaluation of the ability to make decisions regarding the affected domains. A capacity evaluation, however, should include some individualized assessments supported by standardized data and both decisional and executive findings.

**The Articulate step**

In the Articulate step, the clinician targets those domains of self-care and self-protection that are the focus of the neglect assessment (individualized approach) and augments that assessment using standardized evaluation tools for functional, cognitive, affective, or decision-making abilities (standardized approach). The purpose of the 2 approaches in the Articulate step is to establish the capacity of the vulnerable elder to make key decisions central to his or her SC&P.

As part of the individualized approach, the clinician should conduct a traditional medical examination to identify conditions that are common contributors to the self-neglect syndrome, such as depression, delirium, and dementia. Next, the clinician should evaluate the ability of the older adult to make decisions within the context of the 5 domains of SC&P. The focus...
should be on the domains that appear most affected by self-neglect and again be guided by the criteria for decision-making capacity: understanding and appreciation of the problem and potential solutions, reasoning process for weighing the pros and cons of the solutions, and ability to make a choice among the available solutions. Table 1 provides examples of screening questions that can be used in the office to assess appreciation of the problem and possession of a reasoning process for evaluating solutions (page 27). Functional impairment and disabilities alone are not sufficient evidence for defining incapacity. Older adults with functional disabilities should still be capable of describing the roles and expectations of caregivers and be able to direct changes in care plans when important functional tasks are not accomplished.

The standardized approach to the Articulate step provides additional, structured assessments for screening capacity to make decisions about SC&P. Although validated methods for assessing decisional capacity in the context of the domains of medical self-care and personal needs and hygiene are limited, recent approaches such as that introduced by Lai and Karlawish offer clinicians guidance in these evaluations. The Assessing Capacity for Everyday Decisions (ACED) instrument uses this approach and may be adapted to allow assessment of several domains of SC&P. Approaches such as the ACED use the established conceptual framework for assessing decisional capacity and have been validated in the context of the domains of medical self-care and personal needs and hygiene.

Cognitive evaluations, such as the Executive Interview (EXIT), are important adjunct tests in estimating a person’s decision-making ability in the Articulate step. Although such tests do not provide a direct measure of decision-making ability, abnormal EXIT performance has been associated with declines in ADL and IADL and aspects of medical self-care, including the capacity to consent to treatment. Alternatively, the Financial Capacity Instrument (FCI) is a comprehensive instrument used to evaluate judgment, understanding, and appreciation for managing one’s financial affairs and estate, as well as the capacity to perform several executive tasks related to financial transactions; it has been well-validated in research settings. Various tools commonly used by occupational therapists include key domains of the FCI, and referrals for evaluation by an experienced therapist can aid in the clinician’s overall evaluation of capacity.

The capacity to make decisions is a clinical determination involving more than assessments of decision-making ability; therefore, consideration of social and environmental factors that frame these abilities is important. Clinicians may need to collect other information on the patient’s functional, cognitive, and affective states pertinent to his or her SC&P. Geriatric-assessment tools, such as formal ADL and IADL assessments, the Get-up and Go mobility test, the Mini-Mental State Examination, and the Geriatric Depression Scale may provide useful supplementary information to interpret assessments of decision-making ability.

The Demonstrate step

The Demonstrate step is intended to evaluate the executive dimension of capacity for SC&P. When evaluating the capacity to execute decisions regarding SC&P, clinicians should review reports from caregivers and social-services professionals that identify potential declines in the performance of the 5 key domains (see Table 1, page 27). To further investigate potential gaps in the execution of SC&P domains, clinicians should make referrals to nurse practitioners, occupational and physical therapists, and social-services professionals when appropriate. Referrals should be individualized to domains of SC&P that are under investigation. Assessments conducted in the elderly person’s home provide an important opportunity to evaluate the physical state of his or her environment and to probe for any signs of abuse or neglect by designated caregivers. In some circumstances, a comprehensive in-home geriatric assessment by a multidisciplinary team may be indicated. The geriatric team assessment will...
offer the most complete picture of the older adult’s executive capacity, employing both the individualized and standardized approaches. The team assessment is especially helpful in situations in which the vulnerable elder subject is particularly uncooperative or unrealistic regarding his or her impairments.

The Demonstrate step can also include more rigorous testing of the domains of SC&P (standardized approach). Occupational therapists and nurse practitioners can be consulted to perform either home- or clinic-based assessments of functional ability. One particularly useful test in the setting of self-neglect syndrome is the Kohlman Evaluation of Living Skills (KELS), a standardized test that identifies individuals who may lack the skills needed to live independently in the community through the combination of observation, self-report, and performance-based functional assessments of most domains of SC&P. The KELS is a practical assessment tool used by most occupational therapists and can be utilized, with modest training, by most members of the medical team in the clinic or at the patient’s home. Referrals for neuropsychological testing may be warranted to conduct more formal determinations of cognitive and executive abilities. In addition, a psychiatrist can be consulted to conduct a formal psychiatric examination. These examinations are the legal standard for medical determinations of capacity and may guide guardianship rulings.

Prescribing interventions to support capacity

The Articulate Demonstrate method offers a comprehensive framework that can be used by clinicians to identify potential deficits and evaluate the capacity for SC&P in vulnerable older adults. The method is derived from the diverse expertise and clinical experiences of the authors in evaluating older adults’ capacity to make and execute decisions regarding safe and independent living. The Articulate Demonstrate method aims to improve the reliability of capacity assessments performed by busy primary care clinicians caring for vulnerable older adults. This method should serve as a screening process to identify clear impairments in more advanced cases and the need for referral to an appropriate specialist (eg, psychiatrist, neurologist, or geriatrician) for more complex or marginal cases.

Appointment of a guardian or other legal surrogate decision makers and caregivers is a potential option to avoid subsequent placement in long-term care. More commonly, vulnerable older adults can continue to live in the community, despite one or more impairments in decisional or executive capacities. In these scenarios interventions can be designed to ameliorate some or all gaps in the performance of SC&P domains. Interventions should target specific impairments either by supporting the deficits of the vulnerable elderly person (eg, treating symptoms of depression, providing a transfer bench for the bathroom) or by reducing the effort needed to accomplish a task (eg, engaging a home-health nurse to assist with medication management, designating a proxy for financial affairs), following a strategy used to address other types of functional impairments. Follow-up evaluations can then be used to determine the effectiveness of the prescribed interventions and the older adult’s cooperation.

Case resolution

Mrs M clearly fits the clinical presentation of self-neglect syndrome. She is unable to perform the basic tasks required to meet the domains of SC&P, refuses to designate these tasks to appropriate caregivers, and over time develops other geriatric syndromes that result in significant morbidity requiring hospital admission. Once Mrs M’s acute medical condition was treated, she expressed her preference to return home without any additional assistance. A psychiatrist was consulted to perform a formal assessment of her capacity. The psychiatrist reviewed medical records and reports from the home care nurse and the neighbor and conducted an evaluation. He concluded that Mrs M did not possess the capacity to make decisions about
her wound care based on the assessment of her decision-making skills in the context of her social, cognitive, and psychological state. Furthermore, there were significant deficits in her ability to execute her medical self-care and some aspects of maintaining her living environment. Mrs M was permitted to return home with the caveat that she allow regular visits by a home health nurse to supervise wound care and a home aide to assist with IADL because of her limited capacity for SC&P.

**Conclusion**

The Articulate Demonstrate method is practical and efficient for screening capacity in cases of suspected self-neglect. This method may help clinicians target interventions to address deficits that contribute to vulnerability in older adults.

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**References**


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<thead>
<tr>
<th>Articulate decisional capacity</th>
<th>Demonstrate executive capacity</th>
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<tr>
<td><strong>Individualized approach</strong></td>
<td><strong>Individualized approach</strong></td>
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<tr>
<td>Clinician identifies potential gaps in self care and protection (SC&amp;P) domains using standard medical examination. The elder should articulate the ability to make decisions regarding the affected SC&amp;P domains. The elder should identify caregivers and their roles in relation to the affected SC&amp;P domains. Clinician may review additional records to further assess the affected SC&amp;P domains.</td>
<td>Obtain reports from caregivers and social services regarding elder's function in the community. Refer to allied health providers for comprehensive home evaluation of targeted domains of SC&amp;P. Identify potential issues of neglect or abuse related to caregivers. Review progress in medical conditions and cognitive abilities over time.</td>
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<td><strong>Standardized approach</strong></td>
<td><strong>Standardized approach</strong></td>
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**Figure 1.**
Table 1

Screening questions to assess functional domains of capacity for self-care and self-protection

<table>
<thead>
<tr>
<th>Domains of self-care and self-protection</th>
<th>Decisional capacity</th>
<th>Consequential problem solving</th>
<th>Executive capacity (verification of task performance)</th>
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<tbody>
<tr>
<td><strong>Personal needs and hygiene:</strong> Bathing, dressing, toileting, and ambulation in home</td>
<td>Appreciation of problems</td>
<td>If you had trouble getting into the bathtub, how could you continue to bathe regularly without falling?</td>
<td>Physical examination of hair, skin, and nails. Gait evaluation and screening for balance problems and recent falls.</td>
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<tr>
<td><strong>Condition of home environment:</strong> Basic repairs/maintenance of living area and avoidance of safety risks</td>
<td>Do you have any trouble getting around your home due to clutter, furniture, or other items?</td>
<td>What if your air conditioner [or heater] stopped working; how would you fix the problem?</td>
<td>Proxy reports of the home environment or a home safety evaluation performed by an occupational therapist or home health service.</td>
</tr>
<tr>
<td><strong>Activities for independent living:</strong> Shopping and meal preparation, laundry and cleaning, using telephone, and transportation</td>
<td>It is important to make basic repairs to one's home; do any parts of your home need repairs?</td>
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<tr>
<td><strong>Medical self-care:</strong> Medication adherence, wound care, and appropriate self-monitoring</td>
<td>Going to the store is important for buying food and clothing for everyday life. Do you have any problems going to the store regularly?</td>
<td>If you needed to call a friend [a cab or other service] to take you to the store, how would you do that?</td>
<td>Ask patient to use the clinic’s phone and call a friend or other service to ask for a ride. [Patient should demonstrate all steps for making a call and getting information.]</td>
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<tr>
<td><strong>Financial affairs and estate:</strong> Managing checkbook, paying monthly bills, and entering binding contracts</td>
<td>People who forget to take their medications may end up having a worse health condition or need to see the doctor more often. Do you have problems remembering to take medications?</td>
<td>Consider if you had to have someone give your medications to you and watch you take them. How would this affect your everyday life?</td>
<td>Ask patient to bring all medication bottles from home, even empty ones. Review medication fill and refill dates and pill counts, or have a home-health nurse do a home medication assessment.</td>
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<td></td>
<td>What difficulties do you have paying your monthly bills on time?</td>
<td>How could asking [cite individual] to help you with paying your bills be better than managing your monthly income and paying bills by yourself?</td>
<td>Proxy reports of bank statements, uncollections, or bills. Can formally assess performance with routine financial tasks, such as 1- or 3-item transactions, including making change or conducting a payment simulation using a check and register.</td>
</tr>
<tr>
<td></td>
<td>Who can assist you with paying your monthly bills or managing your finances?</td>
<td>Are there any reasons why asking [cite individual] to manage your income might not help or might make things worse for you?</td>
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Table 2

Common presenting signs and symptoms of elder self-neglect

<table>
<thead>
<tr>
<th>Physical examination</th>
<th>Clinical signs</th>
<th>Proxy reports</th>
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<tr>
<td>Unkempt hair, nails, or clothes</td>
<td>Missed medication refills or physician appointments</td>
<td>Dangerous or unkempt home</td>
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<tr>
<td>Unexplained weight loss</td>
<td>Decline in cognitive function</td>
<td>Unpaid bills and debts or evidence of exploitation</td>
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<tr>
<td>Unusual wounds or odors</td>
<td>Frequent acute exacerbations of chronic illnesses and untreated medical diseases</td>
<td>Functional decline in activities of daily living</td>
</tr>
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</table>

Sources: Dyer CB, Goins AM\textsuperscript{7}; and Dyer CB.\textsuperscript{10}