

Cognitive Impairment among Functionally Limited Elderly People in the Community: Future Considerations for Long-term Care Policy

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THERE ARE COMPELLING REASONS TO IMPROVE OUR knowledge of cognitive impairment among elderly people, and, in particular, its functional consequences. The gradual loss of independence resulting from diseases like Alzheimer's and its effects on victims and those caring for them has been graphically depicted in both academic and popular forums. Efforts to develop policy regarding provision of long-term care services, however, have raised a number of questions about the link between cognitive impairment and functional status. Paramount among them is whether functional status measures based on performance of routine daily activities, generally regarded as adequate indicators of the need for long-term care assistance, capture the full range of disabilities resulting from cognitive impairment. If not, some suggest additional functional or behavioral criteria should be considered to extend coverage for services to as many of the cognitively impaired as possible. Evidence that caring for cognitively impaired individuals is particularly stressful is cited in support of this position.

The use of research-based measures of functioning to formulate legislation has made the relation between these measures and cognitive impairment of more than academic interest. Ability to perform "activities of daily living" was the primary basis for eligibility in all major bills proposing coverage of home and community-based long-term care services in the 100th Congress of the United States. Congress's Biparti-

san Commission on Comprehensive Health Care (also called the Pepper Commission) deliberated on similar criteria when they made their far-reaching recommendations to the 101st Congress in March 1990 concerning the United States health care system, including the provision of long-term care.

This article undertakes two tasks. First, to examine the implications for cognitively impaired individuals in the community, and those who care for them, of basing access to long-term care services on activities of daily living (ADLs). Second, to consider the need for alternative approaches, particularly in light of the concern that ADL measures do not adequately address the range of disabilities related to cognitive impairment. The data used for these purposes are from the 1982 National Long-term Care Survey (NLTC). The NLTC is a large complex national survey intended to meet a wide range of analytic goals. Consequently, the appropriateness of its use for any specific analysis rests on a series of judgments. In this instance, these relate to the validity of the determination of cognitive impairment among survey respondents and the representativeness of the study sample for examining cognitively impaired people in the community. These issues are of sufficient importance to justify a detailed consideration of the ways cognitive impairment is assessed in surveys in general, and in the NLTC in particular, as well as the appropriateness of the NLTC sample design for studying the cognitively impaired. The use of datasets such as the NLTC in the policy process continues to grow, making explicit consideration of the assumptions and methods that underlie policy estimates important. In addition, as policy makers become aware that substantially different estimates can be generated from such datasets, there is increasing pressure to clarify both aspects of the data and analytic decisions that may affect results (see, for example, Weiner and Hanley 1989).

Cognitive Impairment: Definitions and Measurement in Community Populations

At present the diagnosis of dementia in treatment settings is a complex and technologically intensive process, so it is not surprising that difficulties arise in the identification of cognitively impaired individuals in the community. Cognitive impairment is not a specific mental disorder.

der. Rather it describes the condition of individuals who are on "a final common pathway of a wide variety of dementing processes" (Gurland 1980). A substantial segment of the cognitively impaired suffer from dementia, described in a recent government report as "the loss of mental functions in an alert and awake individual" (Office of Technology Assessment 1987). The most widely recognized cause of cognitive impairment is Alzheimer's disease, which accounts for somewhere between one-third (Folstein et al. 1985) and two-thirds (Katzman 1986) of prevalent cases of dementia. Other less common causes of cognitive impairment include mental retardation and aphasia resulting from a stroke.

Both the diagnosis of dementia and of the specific disorders causing it are difficult even in clinical settings. Katzman (1986, 965) observed that diagnosis of Alzheimer's is often confounded "by coexisting diseases . . . simply because of the frequency of serious neurologic and systemic diseases in the elderly population." A recent National Institutes of Health (NIH) Consensus Conference (1987) on diagnosis of dementing illnesses recommended using multiple techniques, including complete individual and family histories, lab tests and repeated evaluations, to increase accuracy in the diagnostic process.

Studies of prevalence of cognitive impairment in community populations typically use brief questionnaire instruments developed as screening tools in clinical settings. Clinical evaluations are rarely undertaken. Exceptions include one of the National Institute of Mental Health epidemiologic catchment area (ECA) studies (Folstein et al. 1985) and a recent study in one of the NIA sites of the "Established Populations for the Epidemiologic Study of the Elderly" (Evans et al. 1989). Much of the variation across studies in estimates of prevalence of cognitive impairment has been attributed to the use of a number of different screening instruments as well as to differences among them in sensitivity, specificity, and reliability in assessing presence of cognitive impairment (Wang 1977; Gurland et al. 1980; Jorm, Korton, and Henderson 1987). Despite considerable variation in prevalence estimates of mild cognitive impairment in the elderly population, however (3 percent in Kay's 1972 study and 25 percent in Pfeiffer's 1975 study, from Wang 1977), estimates of severe impairment have consistently fallen in the range of 5 to 7 percent. The most recent challenge to conventional wisdom concerning prevalence rates in the community comes from one of the few studies to perform clinical evaluations of community residents

(Evans et al. 1989). The prevalence of Alzheimer's disease reported is 10.3 percent among people aged 65 or older, substantially higher than the 2 percent with Alzheimer's and the 6.1 percent for dementing illnesses overall, reported by Folstein et al. (1985). Both studies employed clinical evaluations but differ in several other respects including methods of sampling subjects for clinical evaluation and characteristics of the communities being studied—for example, ethnicity. In the context of considering the effects of contrasting assessment methods on estimates of prevalence, it is interesting to note that clinical evaluations that represent the standard of validity for survey instruments do not themselves appear immune to variation.

Among the instruments most commonly used in community surveys as a means of evaluating cognitive functioning are the Mental Status Questionnaire (Kahn et al. 1960), the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer 1975), the Mini-Mental State Examination (MMSE) (Folstein, Folstein and McHugh 1975), the Information-Orientation-Concentration test (Blessed, Tomlinson and Roth 1968), and the Dementia Rating Scale (Mattis 1976). Many were developed using institutional patient populations (evaluating the instrument on its ability to identify accurately people known to be cognitively impaired). In general, they have proved to be reliable on repeated administration and valid compared with clinical judgments. Folstein et al. (1985) conducted a two-stage study in which the Mini-Mental State Examination was administered and those with low scores then received a psychiatric clinical examination. These researchers found that for persons with very low scores, representing the severely impaired, all but 14 percent had diagnosable disorders according to criteria using the *Diagnostic and Statistical Manual* of the American Psychiatric Association. When the cut-off was raised, however, one-third had no diagnosis of mental disorder, i.e., a specific dementing condition or other psychiatric disorder. An unpublished analysis by the NIMH ECA research group at Johns Hopkins University shows that performance of the SPMSQ in detecting late life dementia in an elderly household population was essentially equivalent to the MMSE (J. Anthony, personal communication 1989) (see appendix note 1).

Though widely used for research purposes as a means of assessing cognitive functioning, screening instruments for cognitive impairment are not the equivalent of a diagnosis of dementia or of specific disorders such as Alzheimer's disease. For one thing, it is difficult in a cross-

sectional study to document that decline in functioning has occurred, a key feature of the diagnosis of dementia. In addition, it is generally accepted that levels of education affect performance, in that persons with very little education may perform poorly in the absence of cognitive impairment, while those with high levels of education may still perform well despite a decline in cognitive functioning. Some researchers also suggest that race (Fillenbaum et al. 1988) and the presence of conditions such as depression (Cavanaugh and Wettstein 1983) affect performance.

Perspectives on the adequacy of current screening instruments are likely to vary. For clinical purposes they represent only an indication that further evaluation is needed since "proper identification of the disease state responsible for dementia in the individual patient is critical to management" (National Institutes of Health 1987). However, long-term-care policy makers tend to be more concerned with consequences than causes of cognitive impairment. Just as a variety of physical illnesses may lead to a single functional disability—for example, arthritis, stroke, or diabetes may all result in reduced mobility—different dementing disorders may lead to similar types of limitations in daily functioning that require long-term care. Since policy interventions are likely to be in the form of services to those with demonstrable need, identifying specific causes of cognitive impairment is less important in developing policy estimates than identifying people for whom cognitive impairment has functional consequences. Both research on the performance of community survey instruments in detecting cognitive impairment, and the relative consistency of estimates of severe cognitive impairment across studies employing a variety of instruments, suggest current assessment methods provide a reasonable basis for estimates of policy interest for this population. The parameters of the mild or moderately impaired population are subject to more variation, however, and estimates concerning this group are more tenuous.

Constructing a National Profile of the Cognitively Impaired among Functionally Limited Elderly People in the Community

In addition to the generic difficulties of assessing cognitive impairment, there are specific difficulties associated with using national survey data such as the 1982 NLTCS. Two important considerations in the

use of these data for policy estimates concerning functional abilities of cognitively impaired elderly people were raised earlier—the representativeness of the sample and the validity of measures of cognitive impairment.

The National Long-term Care Surveys (NLTCS) were conducted for the purposes of collecting data on elderly people at risk for long-term care (see appendix note 2). In April 1982, a sample of about 36,000 people was drawn from the Medicare beneficiary files. These people were contacted by phone, or in some cases in person, and asked about their ability to perform without help a list of “activities of daily living” (ADLs) and about their ability to perform “instrumental activities of daily living” (IADLs) (see appendix 1). Any problem that had lasted or was expected to last 3 months or longer made the respondent eligible for interview.

In all, 6,393 people aged 65 or older met the screening criteria, and interviews were conducted beginning in May 1982. Of these, 6,088 were interviewed in person using a detailed questionnaire focusing on functional limitations, informal care resources, use of medical services, and personal and household characteristics. About one-quarter of the interviews were completed by proxy respondents because the sample person was “physically or mentally incapable” of responding. (For details of the design and conduct of the surveys see Manton and Liu 1987, and Manton 1988.)

The 1982 NLTCS is representative of the national community-dwelling functionally limited elderly population, as defined by the presence of at least one limitation in an ADL or IADL. Since assessment of cognitive impairment was part of the interview rather than the screening instrument, prevalence of cognitive impairment is restricted to this same population—all elderly people with at least one ADL or IADL limitation.

Examining Cognitive Impairment and Functioning Using the NLTCS

The major concern in using the NLTCS for study of the cognitively impaired among the functionally limited population is whether the criteria for inclusion in the sample, ADL or IADL limitations, include the whole range of functional disabilities that arise from cognitive impairment. Current knowledge about the disabilities caused by cognitive im-

pairment, in the sense of the World Health Organization definition of disability as effects on functional performance and activity, is, in fact, quite limited (Larson 1989). Consideration of what is being assessed by ADL and IADL functioning is useful, however.

The tendency is to view ADL functioning as reflecting physical capacity to perform activities and IADL functioning as reflecting social and behavioral aspects of functioning. A closer look at the development of these indices suggests a better basis for distinguishing between them is that ADLs assess disability in "primary sociobiological functions" such as eating and dressing, while IADLs assess disability in more complex domains that reflect social adjustment to one's environment (Katz and Akpom 1976; Katz and Stroud 1987, 30-32, McDowell and Newell 1987). IADL tasks are more complex. They require a greater range of personal judgment and individual choice, and norms concerning adequacy of performance are less clearly defined (Lawton 1987).

Katz suggests that among ADLs there is a progression in acquiring these skills and that disease-related declines in functioning appear first in those activities that were acquired last and are most complex (Katz and Akpom 1976). Extending this logic, one might expect declines in many IADLs to precede losses in ADL functioning. Recent research suggests such a hierarchy exists (Spector et al. 1987), though there is little evidence concerning the circumstances or inevitability of progressing from IADL to ADL limitations.

Some studies also suggest that IADL limitations are associated with cognitive impairment (Fillenbaum et al. 1988). Clinical descriptions of dementia suggest why this may be so:

Dementia is . . . a syndrome characterized by intellectual deterioration occurring in an adult that is severe enough to interfere with occupational or social performance. The cognitive changes include not only disturbances in memory but also disturbances in other cognitive areas, such as language use, perception, praxis, and the ability to learn necessary skills, solve problems, think abstractly, and make judgments (Katzman 1986).

Early memory problems may be successfully concealed even though the ability "to understand, reason, and use good judgment may be impaired" [p. 8]. Problems in activities such as driving, managing money or forgetfulness in taking medications may occur fairly early in the development of the disease [p. 38]. As the illness progresses, [a person] may be unable to do simple tasks, such as dressing. Dam-

age to the brain begins to affect "many functions, including memory, motor functions (coordination, writing, walking) and speaking. The sick person's abilities may fluctuate from day to day or even from hour to hour. In the final stages, the person is often confined to bed, unable to control urination and unable to express himself. It is important to remember that not all these symptoms will occur in the same person" [pp. 9,10] (Mace and Rabins 1981).

As Lawton notes, IADL functions require a series of complex decisions as well as actions. Shopping for groceries, for instance, requires recognition that food is needed, decisions about which foods to buy, getting to the store, locating the items one wants, selecting among numerous brands, waiting in line, and conducting a payment transaction. Once judgment, reason, and memory are affected, not only the adequacy of performance, but the ability to perform many such activities safely may be threatened. Difficulties performing the complex tasks reflected in IADLs seem likely to coincide with "disturbances" in judgment and the ability to reason that develop relatively early in the disease process. These clinical depictions of dementia also suggest, however, that ultimately the "primary sociobiological functions" reflected in ADLs will be affected as well.

Another type of concern is sometimes expressed about restricting the range of disabilities to ADLs and IADLs. That is, cognitively impaired people often exhibit behavioral problems that are not specifically enumerated, for example, wandering, sleep disturbances, and repetitious actions. Given the previous discussion it seems probable that considerable overlap exists between such behaviors and ADL/IADL performance. Intuitively, an individual who wanders or has other severe behavioral problems commonly associated with cognitive impairment would seem unlikely to be able *without help* to perform the more complex tasks reflected in IADLs, even if simpler tasks such as dressing, bathing, and eating could be undertaken.

A final consideration is that focusing on cognitive impairment within a population known to be functionally impaired by ADL or IADL criteria runs the risk of excluding individuals who are not yet seen by themselves or others as functionally incapacitated. The point at which "intellectual deterioration is severe enough to interfere with occupational or social performance" (Katzman 1986) may be perceived differently depending on what a job requires and what family and friends expect. Furthermore, if functional capacity and behavioral prob-

lems fluctuate as Mace and Rabins (1981) suggest, they may not be viewed as “permanent” problems, i.e., those lasting three months or longer (the standard research definition of the presence of chronic or lasting functional impairment). The problem of unrecognized illness and differences in perceptions of illness as they affect self-reported health and functioning, however, are not specific to the cognitively impaired (Levkoff et al. 1988; Mechanic 1983) (see appendix note 3).

Unequivocal evidence from clinical or statistical studies is lacking regarding the effects of cognitive impairment on various types of functioning and how this changes with stages of the disease. The risk of excluding severely cognitively impaired individuals from consideration seems slim, however, if both ADL and IADL functioning are considered. The NLTCs sample was designed to be representative of the elderly population that is functionally impaired in the broadest sense. Though not designed to address the issue of the functional consequences of cognitive impairment, it captures that segment of the cognitively impaired who have reached the point where their disease demonstrably affects independent performance of one of a wide range of important social and physical activities. Thus, it provides the opportunity to examine, for the population traditionally viewed as at risk for long-term care, the implications of using a small number of limitations in activities of daily living to determine eligibility for services. In addition, the extent to which cognitively impaired people within this group and those who care for them will benefit can be examined.

Defining the Cognitively Impaired in the NLTCs

Identifying those who are cognitively impaired within the NLTCs sample is by means of Pfeiffer’s (1975) “Short Portable Mental Status Questionnaire” (SPMSQ), which is a modification of the “Mental Status Questionnaire” developed by Kahn et al. (1960). The SPMSQ provides indications of intact, mild, moderate, and severe impairment in cognitive functioning based on a scoring of errors in response to a series of 10 questions (see appendix 2). The 4,510 self-respondents who completed the SPMSQ were assigned to categories of cognitive functioning as follows: no impairment (0 to 2 errors), mild impairment (3 or 4 errors), moderate/severe impairment (5 to 10 errors). These cut-off points are recom-

mended by Pfeiffer though there is no consensus within the research community about where the line should be drawn to distinguish levels of severity with this or other scales of cognitive functioning. As Folstein et al.'s study (1985) suggests, the overlap between poor scores on short scales of cognitive functioning and a clinical diagnosis varies according to the cut-off point.

An additional problem, raised earlier as generic to these types of instruments, is whether to adjust scores on the basis of education. Though education is related to test performance, there is disagreement about whether test scores should be adjusted for education and how much (Fillenbaum et al. 1988; Berkman 1986). An adjustment was made for this analysis, allowing persons who had not completed an 8th-grade education one additional error in scoring. This provides for stricter criteria in classifying people as cognitively impaired. Because the NLTC population was a group of elderly disabled individuals, the use of proxy respondents was higher than usual. It was obviously important to obtain information on the most severely impaired within this population; yet, these were the individuals most likely to be too physically or mentally impaired to complete the lengthy interview. Of those with 5 or 6 ADLs, 65 percent had proxy respondents as opposed to 21 percent of those with 1 or 2 ADLs. Those with proxies also were more often aged 85 or older and living with others. Of the total sample, 1,578 cases or 24.7 percent of the interviews were completed by proxy. In these cases the SPMSQ was not administered.

There are alternative approaches to dealing with these cases. The two that appear to introduce the least bias are to keep proxy cases separate (see, for example, Coughlin and Liu 1989, using another dataset with similar problems) or to use other data within the survey to make a determination about cognitive functioning (see appendix note 4). The latter approach has been taken here, drawing on the response of proxy respondents when asked whether senility was one of the sample person's medical conditions. Table 1 records the distribution of self-respondents on the SPMSQ and indicates that among proxy respondents about one-third (533) reported the sample person was senile.

The validity of a proxy report as an indication of cognitive functioning is in question to a greater degree than is self-reported SPMSQ data. There are several reasons for accepting this information as an indication of cognitive functioning. First, it is clear that those respondents with

TABLE 1
Definitions of Cognitive Impairment among the Functionally Limited Elderly Population in the Community^a

	Unweighted sample	Population estimates	
		Weighted ^b	Percentage
Variables indicating cognitive impairment			
SPMSQ for self-respondents:			
Intact	3,582	2,977,000	55.1%
Mild	636	532,000	12.2
Moderate/severe	292	238,000	6.6
Proxy respondents^c reporting sample person as:			
Senile	533	450,000	8.9
Not senile	1,045	877,000	17.3
Total	6,088 ^d	5,074,000	100.0%
Classifications of cognitively impaired elderly			
Any cognitive impairment ^e	461	1,221,000	24.1%
Severe cognitive impairment ^e	825	689,000	13.6%

Source: 1982 National Long-term Care Survey (1982 NLTCS).

^a All elderly people with at least one ADL or IADL limitation residing in the community.

^b Rounded to nearest thousand.

^c Completed the interview for sample person because sample person was "too physically or mentally impaired to complete interview."

^d Excludes 305 nonrespondents to the 1982 survey.

^e Any cognitive impairment was defined as a score of 3 to 10 on the SPMSQ or a proxy report of "senility." Moderate to severe cognitive impairment was defined as a score of 5 to 10 on the SPMSQ or a proxy report of "senility." Under both definitions persons who had not completed an 8th grade education were allowed an additional error on the SPMSQ (4 to 10 = any impairment, 6 to 10 = moderate/severe).

proxies are among the oldest and most severely impaired. There is now substantial evidence that the prevalence of severe cognitive impairment is highest at advanced ages (Evans et al. 1989; Kramer et al. 1985; Gurland et al. 1980; Kay and Bergmann 1980). Thus, rates of cognitive impairment are likely to be higher in the proxy respondent group than among self-respondents, as these proxy reports suggest.

Second, these proxy respondents are likely to be more knowledgeable about the status of the respondent than would be the case for proxies in random surveys of the elderly. The sample consists of functionally impaired individuals and in most instances the proxy is a caregiver. In many cases this is a child or spouse with whom the sample person lives, or is someone who regularly attends to the needs of the sample person. In addition, recent studies suggest that there is strong agreement on assessment of functioning, including assessment of mental status, between elderly subjects and proxies for them, particularly as health worsens (Rodgers and Herzog 1989; Epstein et al. 1989; Bassett, Magaziner, and Hebel 1988).

Third, when both the SPMSQ and proxy data are included, estimates of cognitive impairment in the 1982 NLTCS approximate those from other studies. Table 1 shows under the broadest definition that 24.1 percent of those with some type of functional limitation that manifests in an ADL or IADL are cognitively impaired. The moderately or severely impaired are 13.6 percent of the elderly functionally impaired in the community (see appendix note 5). (For ease of presentation this group is referred to throughout as the severely cognitively impaired.) Using as a base the entire elderly noninstitutionalized population, these estimates would be the equivalent of about 5 percent with any impairment and about 3 percent with moderate/severe impairment, clearly within the range of results from community epidemiological studies undertaken to estimate prevalence of cognitive impairment (though much lower than the most recent prevalence estimates by Evans et al. 1989). These estimates range from 5.1 percent severely impaired in the East Baltimore ECA (Kramer et al. 1985), to 4.6 to 6.3 percent for men and 4.2 percent to 3.6 percent for women across three of the ECA communities (Myers et al. 1984), to 1 to 2 percent severely impaired and 3 to 4 percent moderately impaired in a review of the epidemiology of mental disorders among aged people in the community (Kay and Bergmann 1980).

Coverage of the Cognitively Impaired under Long-term Care Proposals Using ADL Criteria

Most of the proposed legislation for the coverage of community-based long-term care relies on limitations in a core set of ADLs—bathing, transferring from bed to chair or getting in and out of bed, eating, toileting, and dressing. Walking and other mobility activities are generally excluded. Of six major bills introduced in the 100th Congress, all proposed to cover Medicare beneficiaries unable to perform two or more ADLs without human assistance. The language regarding cognitive impairment differed among them, proposing benefits for “those who have a similar level of disability due to cognitive impairment” (Pepper 1987; Melcher 1988; Stark 1988; Waxman 1988), those who have dementia accompanied by a significant behavior problem (Mitchell 1988), or those so cognitively impaired as to require constant care (Kennedy 1988).

Table 2 indicates there are several important implications of using ADL-based criteria alone for eligibility purposes. The number of ADLs chosen as the cut-off point has a substantial impact. Over one-half of the elderly functionally disabled population are covered using a limitation in one or more of the core set of ADLs (53.4 percent), dropping to about one-third using 2 or more limitations (30.8 percent), and one-fifth (18.3 percent) using 3 or more. A similar pattern occurs for the severely cognitively impaired, dropping from about three-quarters covered using 1 ADL to two-fifths using three or more.

At each level, however, a higher percentage of the functionally disabled with cognitive impairment than those without would be covered. Under the most restrictive criteria—3 or more core ADLs—39.1 percent of the functionally disabled with severe cognitive impairment would be covered, compared with 15.4 percent of the functionally disabled with no cognitive impairment. This suggests that among the severely cognitively impaired who have reached the point of observable inability to perform ADLs or IADLs, ADL impairment is widespread. Table 3 provides confirmation, indicating that about three-quarters of the severely cognitively impaired had at least 1 ADL. (Virtually all of the NLTCS population has at least 1 IADL, with only about 4 percent reporting ADLs absent IADLs.)

TABLE 2
 Percentage of the Functionally Limited Elderly Population in the Community Included under Different
 ADL Eligibility Criteria, by Cognitive Status

ADL eligibility criteria	Functionally limited elderly in the community with							
	Total ^a		No cognitive impairment		Any cognitive impairment		Severe cognitive impairment	
	(%)	(in thou.)	(%)	(in thou.)	(%)	(in thou.)	(%)	(in thou.)
Total	100.0	5,074	100.0	3,853	100.0	1,221	100.0	689
Limitations in:								
Any ADL ^b								
One or more of 5 core ADLS ^c	60.6	3,074	58.0	2,235	68.8	839	75.6	521
Two or more of 5 core ADLS	53.4	2,710	50.4	1,941	63.0	769	71.7	494
Three or more of 5 core ADLS	30.8	1,563	27.5	1,059	41.2	503	53.6	369
Three or more of 5 core ADLS	18.3	930	15.4	593	27.6	337	39.1	269
Limitations requiring human assistance:								
Any ADL ^b								
One of more of 5 core ADLS ^c	36.0	1,825	32.2	1,240	47.9	585	62.0	424
Two or more of 5 core ADLS	35.0	1,767	31.0	1,194	46.9	573	60.7	418
Three or more of 5 core ADLS	18.8	954	15.4	593	29.6	361	43.3	298
Three or more of 5 core ADLS	12.2	618	9.2	355	21.6	263	32.8	226

Source: 1982 NLTCs.

^a All elderly people with at least one ADL or IADL limitation residing in the community.

^b The ADLs are bathing, transferring, eating, toileting, dressing, and getting around inside.

^c The 5 core ADLS most often used in current legislative proposals care are bathing, transferring, eating, dressing, and toileting.

TABLE 3
Types of Limitations in Functioning and Need for Human Assistance
among the Functionally Limited Elderly Population in the Community

Functional limitations and need for assistance	Total ^a	No cognitive impairment	Any cognitive impairment	Severe cognitive impairment
Presence and number of ADLs and IADLs^b				
One or more of 6 ADLs	60.3%	57.8%	68.4%	75.5%
IADLs only	39.7%	42.2%	31.6%	24.5%
Average no. of ADLs	2.6	2.4	2.9	3.3
Average no. of IADLs among those with IADLs only	3.0	2.8	3.6	4.3
Assistance with ADLs				
Personal help only ^b	17.1%	15.9%	20.5%	24.8%
Personal help and equipment	42.1%	39.4%	49.1%	56.6%
Equipment only	40.8%	44.7%	30.4%	18.6%
			(<i>p</i> < .001)*	(<i>p</i> < .001)*

^a All elderly people with at least one ADL or IADL limitation residing in the community.

^b ADLs are bathing, dressing, eating, toileting, getting in and out of bed, and getting around inside. IADLs are heavy work around the house (scrubbing floors, washing windows), light work around the house (straightening up, washing dishes), doing laundry, preparing meals, shopping for groceries, getting around outside without assistance, managing money (keeping track of bills), taking medicine if needed without assistance, making phone calls without assistance.

* *p* value for Wald's Q-scores testing homogeneity of selected characteristics (presence of ADLs, type of assistance for the ADL impaired) for functionally limited elderly with any cognitive impairment versus those with none, and functionally limited elderly with severe cognitive impairment versus all others.

Finally and importantly, however, these data confirm that use of ADL-based criteria alone would not extend coverage to all of the severely cognitively impaired. Under the most commonly proposed criteria—inability to perform 2 or more ADLs—only about one-half would qualify for coverage. Among those with IADL limitations only, excluded under any ADL criteria, the severely cognitively impaired are more disabled, having on average 4.3 limitations versus 2.8 for the larger IADL-only population without cognitive impairment.

Adding the need for human assistance as an additional eligibility screen reduces the covered population further (table 2). Assistance with IADLs, because of the nature of the tasks, is provided almost exclusively by other people. Those who are ADL-impaired, however, may rely on personal assistance, may use equipment, or may combine the two (see appendix note 6). Extent of coverage among the severely cognitively impaired is less affected by this additional restriction. Table 3 suggests why. Severely cognitively impaired people among the functionally disabled rely much more on personal assistance. It seems plausible that the impairments in judgment, reasoning, and ability to learn, described in the clinical literature as consequences of dementia, may affect one's ability to rely independently on equipment to compensate for disabilities.

The Implications for Caregivers of ADL-based Eligibility Criteria

Assistance to functionally disabled elderly people in the community is overwhelmingly the purview of family members (Doty 1986; Stone, Cafferata, and Sangl 1987). There are numerous studies investigating the stress associated with the caregiver role (cf. Cantor and Little 1985). Some of this research indicates that caring for someone who is cognitively impaired is particularly stressful for reasons that include having to cope with aberrant behaviors (Pruchno and Resch 1989) or the need continually to supervise activities (Silliman and Sternberg 1988).

Caregiving arrangements take many forms, but of major importance is the availability and willingness of family members to assume this role. Among spouses to functionally limited people, almost all are involved as a caregiver in some capacity (only 6 percent of married people in the NLTCS give no indication of assistance from their spouse). Caregiving arrangements for people with no spouse caregiver who have children may be restricted to children, include other helpers, or be limited

to other helpers only, whereas those who are childless have fewer options (13 percent of the functionally limited elderly had neither a spouse nor a child and are excluded from table 4 but included in tables 5 and 6).

The presence of severe cognitive impairment or an ADL limitation increases the likelihood that others will assist a spouse in providing help (table 4). The likelihood of additional help to spouses is greatest in the presence of both ADL limitations and severe cognitive impairment (spouse with others is 2.34 times as likely as spouse alone).

The presence of ADL limitations also increases the likelihood that children will seek out other helpers (twice as likely that caregivers are children with others rather than alone). But the presence of cognitive impairment does not. It does, however, appear to be a significant deterrent to turning caregiving over to someone outside the immediate family. Both severe cognitive impairment by itself, and in combination with ADL limitations, increases the likelihood that children will retain responsibility for caregiving, whether from choice or necessity.

Given these findings, it is not surprising that among severely cognitively impaired people, 50.3 percent overall, and 62.2 percent of those with children, receive assistance from their children (table 5). The percentages are actually greater since some of the "others" assisting a spouse caregiver are also children. Caregiving arrangements are quite different between the 80 percent of severely cognitively impaired people with children and those without. Spouse caregivers to people with children are less likely to shoulder this responsibility alone. In the absence of children, almost two out of three spouse caregivers to the severely cognitively impaired are sole caregivers, compared with 2 out of 5 among those with children (from table 6). Three-quarters of those without children rely on siblings or people outside their immediate family for help.

Overall, 43 percent of severely cognitively impaired people would be eligible for access to formal long-term care services using criteria of two or more ADLs requiring human assistance. Coverage is not uniform across caregiving arrangements, however. Between 55 and 60 percent of people being cared for by spouses with other assistance and children with other assistance would be covered (table 6). This is in keeping with the finding that presence of ADLs is related to obtaining additional assistance (table 4). In contrast to people with children, among those with none, a higher percentage of people with only a spouse caregiver (37 percent) or other caregivers (32 percent) would be covered. This is further evidence that spouse-only caregivers in the absence

TABLE 4
Effects of Cognitive Impairment and Presence of ADL Limitations on Probability of Multiple Caregivers and Type of Caregiver for Functionally Limited Elderly People in the Community (Logistic Regression)

Cognitive status and type of limitation	People with spouse caregiver ^a				People with children and no spouse caregiver ^b					
	Spouse alone (0) vs. with others (1)		Child alone (0) vs. with others (1)		Others only (0) vs. child alone or with others (1)					
	Beta coeff.	SE	Odds ratio		Beta coeff.	SE	Odds ratio	Beta coeff.	SE	Odds ratio
Main effects only										
Intercept	-.82+	.09	--		-.55	.09	--	1.22+	.08	--
Mild cognitive impairment ^c	.15	.16	--		.24	.15	--	.30	.17	--
Severe cognitive impairment ^c	.58+	.15	1.79		.02	.12	--	1.08+	.16	2.96
At least 1 ADL ^d	.72+	.10	2.06		.68+	.11	1.98	.02	.10	--
Main effects & interaction terms										
Intercept	-.78+	.10	--		-.50	.11	--	1.26+	.09	--
Mild cognitive impairment	.34	.30	--		.23	.24	--	.31	.25	--
Severe cognitive impairment	-.07	.32	--		-.34	.26	--	.55+	.27	1.74
At least 1 ADL	.66+	.10	1.94		.61+	.13	1.84	-.04	.11	--
Mild and any ADL ^e	-.27	.36	--		.01	.31	--	-.03	.32	--
Severe and any ADL ^e	.85+	.33	2.34		.47	.31	--	.76+	.35	2.14

+ T-statistic > 2.0 indicating statistical significance at the .05 level.

^a Includes all persons who named their spouse as a caregiver. Among those with a spouse, 94% named their spouse as a caregiver.

^b Child caregivers include daughters, sons, daughters-in-law, and sons-in-law. Other helpers include siblings, other relatives, friends, people from helping organizations, and other paid and unpaid helpers. Excluded are persons with no children who have no alternative but to rely on other helpers.

^c Reference group is people with no cognitive impairment.

^d Reference group is people with no ADL impairment.

^e Reference group is people with no cognitive impairment and no ADL impairment.

TABLE 5
 Caregiving Arrangements for Severely Cognitively Impaired People Overall
 and by Presence of Children

	Total	People with children ^a	People without children
Total	100.0%	80.5%	19.5%
Spouse only	12.8	12.1	16.0
with others ^b	17.7	19.9	8.3
Child only	25.1	31.1	—
with others	25.2	31.0	—
Others only ^c	19.2	6.0	75.7

^a Includes daughters, sons, daughters-in-law, and sons-in-law.

^b Children or any other helper.

^c Includes siblings, other relatives, friends, people from helping organizations, and other paid and unpaid helpers.

of children are caring alone for more impaired people. It should be noted as well that overall a lower percentage of people without children are covered (35.6 percent) in contrast to those with coverage (46.8 percent). There may be a different distribution of ADL limitations in these populations. It is also possible that fewer of the severely cognitively impaired among those without children are able to remain in the community, and these data reflect a greater likelihood of institutionalization among this group.

About one-quarter of the severely cognitively impaired population would not be covered under any ADL criteria because they are limited in IADLs only. This also varies by caregiving arrangement. Among people who are cared for by a spouse only, 37 percent would not be covered. About one-third of those cared for only by their children would not be covered.

One concern in the development of formal services for long-term care in the community is that they supplement and support the efforts of the family. By considering the strength and availability of the family support system in addition to the functional disabilities of the potential recipient, it might be possible to provide increased assistance to fragile informal care arrangements. Whether some caregiving arrangements to the severely cognitively impaired are more fragile and present greater risk for the well-being of the recipient or the caregiver requires more research on caregiving over extended periods of time. Given that addi-

TABLE 6
Coverage of Severely Cognitively Impaired People Using ADL-based Criteria
by Caregiving Arrangements

	Total ^a (in thou.)	% covered using 2+ ADLs requiring human assistance	% not covered because limited in IADLs only
All caregivers	689	43.3	23.1
Spouse only	85	30.8	37.2
with others	118	61.1	11.5
Child only	168	39.7	32.3
with others	167	56.1	14.0
Others only	129	30.6	24.9
People with children	555	46.8	22.9
Spouse only	65	28.5	37.1
with others	107	61.2	9.4
Child only	168	39.7	32.3
with others	167	56.1	14.0
Others only	32	25.0	37.4
People without children	134	35.6	24.1
Spouse only	20	37.4	37.4
with others	11	59.5	33.2
Others only	97	31.6	20.7

^a Caregiver subgroups do not add to totals because 3.2% of cases overall—2.9% of people with children and .4% of people without children—for whom no caregiver data were available are not shown.

tional help to spouse caregivers is associated with severe cognitive impairment (table 4), spouses who are unable to obtain help may be at risk for greater stress and problems with caregiving. In addition, reliance on largely unpaid caregivers from outside the immediate family, which occurs most extensively among people without children, may be precarious as well.

Conclusion

Providing services to elderly people in the community in need of long-term care continues to be a major focus of health policy for the elderly. This analysis suggests that using ADL functioning to determine access

to home and community-based long-term care services will not exclude the cognitively impaired from coverage, as some have feared. About one-half of the severely cognitively impaired would be covered, using limitations in 2 or more of 5 basic ADLs as eligibility criteria for access to formal long-term care services. Adding a requirement for active personal assistance with ADLs as a means for further restricting the eligible population would have less effect on extent of coverage for the cognitively impaired, more of whom rely on other people for assistance. Since policy responses in the long-term care arena are likely to be incremental, ADL-based eligibility criteria appear to be a reasonable first step in extending coverage to disabled people regardless of the nature of their underlying impairment, e.g., physical or cognitive.

Extending coverage to more of the severely cognitively impaired requires additional eligibility criteria. Though IADL limitations and brief cognitive assessment instruments have potential utility, neither is generally viewed as a serious candidate. There appear to be several reasons.

IADL limitations have several drawbacks. While limitations in ability to perform many of these activities are undoubtedly affected by cognitive impairment, IADL limitations are prevalent among people with no cognitive impairment as well. In other words, IADL limitations may be sensitive to cognitive impairment (almost all cognitively impaired people have such limitations) but not specific to cognitive impairment (many persons without cognitive impairment have these limitations as well). Thus, too broad a net of eligibility is cast by IADL limitations.

In addition, many people are uncomfortable with using as eligibility criteria the types of activities typically represented in IADLs. Preparing meals or shopping are seen as less clearly linked to health and more subject to individual inclination. Though it is rarely made explicit, current long-term care legislation seems intended to identify and assist those whose functioning has declined as a result of disease processes. ADL performance works well in this regard since these activities reflect basic "primary sociobiological functions" (Katz and Akpom 1976) that most disabled elderly people at earlier points in their lives could master. Declines in these areas are accepted as the consequence of disease processes even when specific underlying diagnoses are not established. The link between declining health and inability to perform the types of social and behavioral tasks that form the IADLs is weaker. It is weaker because performance of these more complex tasks is affected by personal judgment and choice (for example, whether one is willing or

views it as necessary to do the tasks, not merely whether one is capable) as well as social and cultural influences as to the appropriateness of specific tasks for specific people (Lawton 1987). Causes of nonperformance reflecting individual preferences not to do certain tasks would certainly not be viewed as appropriate justification for access to publicly funded long-term care services. The process of separating justifiable from non-justifiable causes of nonperformance might prove difficult, however.

Finally, even if the causal link between poor health and IADL performance were stronger, many of these activities fall into the realm of homemaker or chore services, which often are viewed as less critical to continued independent functioning in the community. More empirical evidence as to the accuracy of this assumption and important extenuating circumstances in which it may not hold would be valuable.

Cognitive-status screening instruments also are viewed with skepticism as eligibility criteria. They are seen as susceptible to "gaming," in addition to their acknowledged specificity problems. An equally important reason why these instruments may be unsuitable in a long-term care eligibility context, however, is that they reflect a concern with diagnosis rather than functioning. It is generally felt that long-term care services should be directed to people based on their functional needs in routine daily life. Diagnosis of specific diseases is a poor indicator of functioning especially for the elderly, whether arthritis or cognitive impairment is being considered (Rowe 1985).

Given these concerns, there are still ways in which further research can contribute to the policy process by suggesting means of extending coverage to the cognitively impaired. One is to investigate extending or reconsidering assessment of functioning. Katz's original assessment by observation of ADL performance clearly allowed for a cognitive component in functional dependence. For example, people were regarded as dependent if they were regularly supervised in bathing or transferring or remained partly undressed (Katz and Akpom 1976). In survey interviews, however, to elicit information about an activity such as dressing, the question asked is whether a person had difficulty dressing because of a health problem (1984 NHIS Supplement on Aging) or whether anyone helped the subject dress (1982 NLTCs). Clearly, many cognitively impaired people or those who care for them will indicate difficulty or the need for help. It is possible, however, that a person can dress but frequently forgets and must be reminded, puts on inappropriate clothing such as winter clothes in the summer, or fails to fasten clothing. Unlike the original approach to assessment, there is little

good evidence concerning how survey respondents view these types of deficiencies and report them in response to queries about ADL performance. Broadening the scope of ADL performance may have implications both for translating ADLs into eligibility assessment tools and for survey-based policy estimates.

Another means of broadening assessment of functioning that should be explored is whether adding certain types of behaviors, such as wandering, to the set of ADLs typically used, encompasses individuals not already identified through ADL limitations alone. Similarly, more investigation of the link between IADL functioning and cognitive impairment, and, in particular, whether limitations in particular IADLs more specific to cognitive decline can be identified, is warranted.

Efforts to identify additional eligibility criteria for the cognitively impaired take for granted that it is particularly important to extend coverage to this population. One reason is the perception that care of the severely cognitively impaired represents a significant burden for family members. There is research to suggest that cognitively impaired people require a greater amount and intensity of caregiving (Horowitz 1985; Silliman and Sternberg 1988), though few studies directly compare physically and cognitively impaired people on this dimension. In this analysis, presence of cognitive impairment was an important factor in seeking out additional help by spouse caregivers. Children often provide this additional help and, in the absence of spouse caregivers, the burden of caring for the cognitively impaired rests with children. These patterns do not directly reflect burden or stress. They do suggest, however, that providing help to severely cognitively impaired people is often too great a burden for an elderly spouse alone, and that children of severely cognitively impaired people are almost universally involved in assisting them. More broad-based evidence concerning the effects on families of assisting people whose ability to function independently is in decline can contribute to policy considerations of eligibility and service needs as well.

Inability to perform ADLs, which represent basic aspects of independent self-care, represents a first stage in the process of identifying criteria that might be used to determine eligibility to formal long-term care services in the community. It is now necessary to consider whether there are additional types of functioning that should be regarded as so crucial, or certain levels of caregiving that are so burdensome, as to form the basis for expanding proposed eligibility criteria. Resolving this issue requires learning a good deal more about the relation between various

types of functioning and cognitive impairment, and the consequences of these relations for individuals and their families.

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Acknowledgments: This research was supported by a grant from the Public Policy Institute of the American Association of Retired Persons and by a Biomedical Research Support Grant from the Johns Hopkins University. The views expressed are those of the author alone.

Peter Rabins, M.D., and Diane Rowland, Sc.D., both of the Johns Hopkins University, provided many helpful comments on this manuscript, as did anonymous reviewers for this journal. John Hanfelt of the Johns Hopkins University provided data-processing support for this research.

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Appendix Notes

1. A "Receiver Operating Characteristic" analysis indicated the MMSE achieved slightly higher sensitivity values (identification of true cases) than the SPMSQ, but at a cost in the form of more false positive errors. SPMSQ sensitivity was in the range of 60 to 80 percent before it yielded false positives.

2. Funding for the 1982 survey came from the Health Care Financing Administration (HCFA) and the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services. Funding for the 1984 survey was provided by HCFA and the National Center for Health Services Research.
3. How ability or inability to perform a task is interpreted is a complex issue, and one that extends to all types of functioning. Self-reported assessments may differ from those of medical professionals. Performance-based measures provide another standard. Though these are important issues in both a research and program eligibility context, they are beyond the scope of the present discussion.
4. There are other approaches that were considered and rejected. One is to leave out the proxy cases. Likelihood of cognitive impairment, however, is greater in the proxy group given their advanced age and that the reason for proxies was "too physically or mentally impaired to complete interview." Leaving out these cases would introduce more bias in the overall estimates (Cox and Cohen 1985). A second approach is to impute cognitive status for proxy cases from known cases. While statistically feasible, there is little face validity to such an approach given current knowledge about the factors that predict cognitive impairment.
5. The 1984 NLTCS provides another cross-sectional sample of the elderly population (Manton and Liu 1987). Estimates of cognitively impaired elderly people among the functionally limited community population in 1984, adjusted for education, were 22.2 percent with any impairment and 12.3 percent with severe impairment.
6. Equipment in the NLTCS covers a broad range of devices including special utensils for eating; wheelchairs, railings, walkers, or canes for mobility; special clothing or equipment for dressing; shower seats, tubs tools, or grab bars for bathing; and special underwear, raised toilets, bedside commodes, or bedpans.

Appendix 1

An answer of "yes" to any of the following and a problem of 3-months duration or one expected to last that long made the respondent eligible for interview.

ADLs

Do you have any problem—

- a. eating without the help of another person or special equipment?
- b. getting in or out of bed without help?
- c. getting in or out of chairs without help?

- d. walking round inside without help?
- e. going outside without the help of another person or special equipment?
- f. dressing without help?
- g. bathing without help?
- h. getting to the bathroom or using the toilet?
- i. do you have any accidents or any problem controlling bowel movements or urination?

IADLs

Are you able to—

- a. prepare meals without help?
- b. do laundry without help?
- c. do light housework such as washing dishes?
- d. shop for groceries without help?
- e. manage money, such as keeping track of bills and handling cash?
- f. take medicine without help?
- g. make telephone calls without help?

Appendix 2

SPMSQ from the NLTCs

Sometimes when people get older, they have trouble remembering things. If you do not know the answers to some of the next questions, that's okay. It's very normal. If you DO know the answers, the questions may seem very simple.

- 1. What is the date today?
- 2. What day of the week is it?
- 3. What is your street address?
- 4. In what state is this?
- 5. How old are you?
- 6. When were you born? Month-Day-Year
- 7. Who is the President of the United States now?
- 8. Who was the President just before him?
- 9. What was your mother's maiden name?
- 10. Subtract 3 from 20 and keep subtracting 3 from each new number you get, all the way down.