AHCPR Studies Examine Impact of Disabilities in the Elderly

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Family and friends provide the bulk of long-term care to elderly patients living in a community. When functional impairment is involved, the social, emotional, and economic costs for members of the family increase dramatically. Family physicians need to be aware of the magnitude of this problem, the potential impact on patients other than the elderly, and the availability of community-based and in-home services that may relieve some of the burden on the caregivers. Five recent studies from the Agency for Health Care Policy and Research contribute to an understanding of the magnitude of this problem in the US population.

One-fifth of the US elderly are functionally limited. Based on data from the National Medical Expenditure Survey (NMES), 21% of the noninstitutionalized population aged 65 years and older have difficulty with at least one activity of daily living (ADL) or instrumental activity of daily living (IADL), or have trouble walking. ADLs refer to basic hygiene and self-care tasks, such as bathing, toileting, and dressing, while IADLs include activities such as shopping, house cleaning, cooking, and managing money. The NMES was conducted between 1987 and 1989 and gathered interview data from 36,400 individuals in nearly 15,000 households.

The most common ADL problems reported in order of frequency included bathing, walking, bed or chair transfer, dressing, toileting, and feeding. Nearly 8% of the noninstitutionalized elderly report difficulty walking. Most persons with ADL difficulties report the need for personal assistance; the majority of those who cannot walk alone rely on equipment, such as walkers and wheelchairs. The most frequent IADL difficulty involves getting around the community and shopping. Individuals with IADL problems are dependent on other persons for help in accomplishing routine tasks.

Relatively few persons 55 to 64 years of age report any ADL or IADL limitations, but the frequency rises after age 65 and climbs sharply after age 80. The ratio of women to men also increases with advancing age and rises sharply beyond age 80. Relatively higher reported frequencies are found among blacks, Medicaid-eligible patients, and persons who do not live with spouses, including widows. (*Leon J, Lair TJ. Functional status of the noninstitutionalized elderly: estimates of ADL and IADL difficulties. NMES Research Findings 4, DHHS publication No. (PHS) 90-3462, June 1990.*)

More than 13 million persons have a disabled elderly parent or spouse. The extent of the effect of informal caregiving was examined by another study that analyzed data from the 1984 National Long Term Care Survey, which included a nationally representative sample of the chronically disabled elderly. This study estimates that one in every six persons 45 to 64 years of age and one in 11 persons working 30 or more hours per week have a disabled elderly parent or spouse and are therefore potential informal caregivers. Less than 1% of the full-time labor force, however, are currently primary caregivers, although women working full time are over four times more likely to be primary caregivers than men.(*Stone RI, Kemper P. Spouses and children of disabled elders: how large a constituency for long-term care reform? Milbank Q 1989; 67:485–506.*)

Competing demands of employment and elder caregiving. Nearly one in every four informal caregivers has to alter work patterns or take unpaid leave to accommodate taking care of a disabled elder, according to a recent study by Robyn Stone, DrPH, and Pamela Farley Short, PhD, of the AHCPR. The study examined the employment decisions of 1000 informal caregivers to determine the degree to which work competes with caregiving responsibilities, how the likelihood of competition between these demands varies among caregivers, and

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whether the probability of conflict discourages caregivers from working at all.

Only about 7% of the group reported having had to quit work to become a caregiver. Not surprisingly, the disabled elder's care needs have a significant effect on employment decisions. What is surprising, however, is that the level of disability, as measured by ADL limitations, is not a significant predictor of employment decisions. Instead, the elder's behavioral state and the amount of supervision required contribute most directly to the conflict between employment and caregiving. The authors suggest that current and proposed elder care assistance programs' use of the severity of ADL limitations as the primary criterion for eligibility could be more effectively targeted on need if more comprehensive measures of functional capacity were developed and incorporated into the criterion. (*Stone RI, Short PF. The competing demands of employment and informal caregiving to disabled elders. Med Care 1990; 28:513–26.*)

Disabled elderly's use of home and community services examined. Estimates based on early data from the 1987 NMES suggest that very old women, persons with difficulty in several activities of daily living, persons living alone, and Medicaid recipients are the most common users of home and community services among the elderly with functional difficulties. Home-based care includes homemaker services and home-delivered meals as well as care provided by home health aides, nurses, and physicians. Community services include senior centers, group meals, and special transportation for the elderly or disabled.

Overall, however, the use of formal home and community services is rather limited, and the functionally disabled rely heavily on informal help from family and friends. Roughly 36% of the 5.6 million noninstitutionalized Americans 65 years of age or older with functional difficulties use formal services. Nearly one-fourth use home-based services, especially for housekeeping and meals; a much lower proportion use community-based services. (*Short PF, Leon J. Use of Home and Community Services by Persons Ages 65 and Older with Functional Difficulties. National Medical Expenditure Survey research findings 5, DHHS publication No. (PHS) 90-3466, September 1990.*)

Large percentage of elders face nursing home use. Forty-three percent of all Americans who turned 65 in 1990 will use a nursing home at least once during the remainder of their lives, according to estimates by researchers at AHCPR. The projections are based on analysis of a national sample of Medicare beneficiaries aged 65 years and older who died between 1982 and 1984. The likelihood of entering a nursing home after age 65 years is higher among women than among men (52% and 32%, respectively), higher among whites than among blacks (38% and 22%, respectively), and higher among those living in the West and the North Central region. (*Murtaugh CM, Kemper P, Spillman BC. The risk of nursing home use in later life. Med Care 1990; 28:952–62.*)

Discussion

The studies reviewed here reveal the startling frequency and magnitude of functional disabilities in the elderly and the impact they have on the individuals and families affected. The observations that 20% of individuals over the age of 65 years have a measurable functional limitation and that one in six people between 45 and 64 years of age have a disabled spouse or parent are dramatic. These data suggest the need for family physicians to be sensitive to the ever-present possibility that the patient may either suffer a functional disability or be responsible for a portion of the care of a functionally disabled person.

Family physicians have the unique opportunity to study the full range of impact that functional impairment may have on both the patient and the family, as well as the effect of preventive and therapeutic strategies. Additional studies are needed that examine the impact of caregiving by family and friends and the effect this may have on the health and well-being of the caregivers. What is the effect of functional disability on patient adherence to suggested treatment? What is the effect of elderly care-giving on the health status and quality of life of the caregiver? Why are community-based home care services not more widely utilized? What proportion of the functional disability is preventable? What proportion is amenable to rehabilitation? What kind of support, advice, and assistance can the family physician provide to the family and caregivers of disabled elderly? Can the physician assist families in developing strategies for the care of elderly patients that would reduce subsequent reliance on nursing home care? What are the components of care that delay or prevent nursing home placement?

Family physicians are also uniquely positioned to develop and test better and more meaningful measures of functional capacity. The widely used measures of ADL and IADL are inadequate to measure the burden placed on families and society by the population of disabled people and to evaluate the effectiveness of strategies designed to maximize the quality of life for both the patient and the caregiver. Improved measures might incorporate the six dimensions of being handicapped as reflected in the WHO International Classification of Impairment, Disability, and Handicap that include orientation, physical independence, mobility, occupation, social interaction, and economic self-sufficiency.