Interventions for family caregivers of patients with Alzheimer's disease in community-based settings: items for consideration

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There is a need for more rigorous evaluation research on existing services for Alzheimer’s disease (AD; e.g., specialized day care, respite care, etc.). The needs, resources, and responses of rural caregivers, and the development, implementation, and evaluation of innovative services where they do not exist are of particular interest.

We must improve the accessibility of diagnostic services in rural areas (e.g., mobile or traveling diagnostic clinics, coordinated by local healthcare professionals, with referral to local resources for follow-up). Issues to address include establishment of standardized diagnostic criteria to rule out reversible dementias and to use in research. Further, the impact of a public education campaign in rural areas, designed to communicate the value of accurate diagnosis and expectation of care needs, must be evaluated. As an integral part of the diagnostic evaluation, a follow-up network (coordinated by the area agencies on aging) that could facilitate the development of a statewide AD registry, making AD a reportable disease, can be considered. In turn, this would enhance epidemiological research efforts and assist in the efficient and standardized collection of data for clinical and research purposes, as well as aid state governments in planning for future care needs.

In many rural areas, the service delivery system is impoverished and fragmented and has insufficient health, mental health, and social services to be supportive of the AD caregiver. Most services, such as nutrition and transportation, are offered only in the county seat and not in smaller communities. For example, there are only 25 adult day-care programs in the entire state of Iowa, and only 13 of 99 counties have case management services—all based in larger towns. Even where chore and companion services are available, in reality rural caregivers have limited access to them because there are few mechanisms for communication and articulation of available services. There also is a lack of availability of diversified healthcare professionals, and most rural nursing
homes do not offer the full complement of healthcare services (e.g., occupational therapy, physical therapy, social services). Many home care programs are based in struggling rural hospitals and also lack the full range of services. More training grants to increase the knowledge base and the supply of rural practitioners working with persons with AD and their caregivers are needed.

The need is especially acute in the area of counseling and mental health services, to assist caregivers in dealing with burden, anger, and depression, and in coping with the behavioral and emotional manifestations of AD. Outreach programs, based in community mental health centers—especially those in rural catchment areas—should receive service demonstration grants (with rigorous evaluation components) to provide comprehensive outreach, mental health, and support-group programs for persons with AD and their caregivers. Questions that arise include the following: Would dementia-specific training programs for professionals in rural health and mental health agencies, nonprofessional staff (e.g., nurse’s aides), informal care providers, and others (e.g., clergy, police, attorneys) improve access and use of counseling by caregivers? What mental health outcomes could then be detected? What mechanisms for communication with primary caregivers about existing services are most effective in rural areas (e.g., statewide clearinghouse to disseminate information on AD, case management programs, increased training of respite workers)? Establishment and evaluation of information/dissemination mechanisms in rural settings are important, because many of these caregivers are isolated, the cost of long-distance phone calls prohibits some caregivers from inquiring about services, and there is no central repository for current and accurate information on resources, regulations, and so forth.

In a recent survey of 107 rural Iowa caregivers, only 51% reported that they used any community-based services, at an average cost to them of $73.44, largely borne out of pocket. More research is needed on how to develop and pay for “user-friendly” services in rural areas. Caregivers reported that they were motivated by a Christian ethic in their caregiving responsibilities, and that God helped them in their caregiving efforts. Many reported a deep sense of personal satisfaction and growth from the experience. More research is needed on the care values and outcomes desired by family caregivers, documenting how (if at all) family values change over the course of the disease, as well as what interventions enhance or maintain positive caregiving experiences. The role of religious values and spirituality and cultural norms must be examined more systematically and in depth. Respondents also indicated that they were not interested in resources outside of family and friends, in part because they were concerned in their rural communities that confidentiality would be a problem, or that help from agencies would be “too close to charity.” These values and beliefs and the stigma associated with use of counseling services may account for (at least partially) the low use of formal services reported in this study. This phenomenon deserves further investigation.

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