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Information and Service Needs of Persons With Alzheimer's Disease and Their Family Caregivers Living in Rural Communities

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This study aimed to identify the information and service needs of persons with Alzheimer's disease (AD) and their family caregivers living in rural communities and to assess differences and similarities in each partner's perspective. In an outpatient clinic setting, a self-report survey was completed by 100 caregivers, while a similar survey was used to interview 100 persons with mild to moderate AD. The survey assessed respondents' interest in information or services related to 22 topics about AD and various aspects of coping with the disease. Although more caregivers than persons with AD reported interest in each topic, 8 of the top 10 topics endorsed by each group of respondents were the same. However, analysis of responses by dyads revealed substantial disagreement in terms of each partner's interest in information and services. Patient and family education, as well as referrals for services, must take into account each partner's unique perspective and needs.

Keywords: Alzheimer's disease; information and service needs; persons with dementia; family caregivers; rural communities

There are 59 million Americans living in rural areas, or about 21% of the total US population, based on criteria used in the 2000 census.[1,2] Obstacles faced by patients and family caregivers (CGs) in rural areas are different from those in urban areas. Rural Americans face a unique combination of factors that create disparities in health care and social services not found in urban areas. For example, less than 10% of physicians practice in rural areas.[3] Lack of health care services contributes to poorer health and both higher morbidity and mortality rates from all causes among rural residents compared to urban residents.[4] Economic, cultural, educational, and social differences present major challenges in coping with chronic medical conditions such as Alzheimer's disease (AD) and related dementias.

Because of the paucity of dementia studies in rural populations, it is difficult to determine prevalence rates, but there is reason to believe that dementia may be more common in rural America than in urban areas.[5] There are currently an estimated 4.5 million Americans with AD.[6] Assuming an equal proportion of rural residents have AD, 21% of 4.5 million Americans (or more than 1 million people) in rural areas probably have the disease. However, very little is known about the needs of persons with AD and related dementias or their family CGs living in rural areas.

A few studies have focused primarily on barriers to service utilization by rural families caring for relatives with dementia.[7-9] Several studies have identified the needs of rural CGs. Fortinsky and Hathaway[10] surveyed 104 past and present CGs in Maine via telephone and identified a critical need for high-quality educational material throughout the caregiving career as well as information about respite care and other support services. CGs in northwestern Ontario, Canada (N = 68), identified a greater need

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for disease-related information and emotional support than practical assistance with care tasks.[11] CGs (N = 114) in Kansas identified a range of needs including information about the disease, planning for the future, respite care, and emotional support.[12] Wackerbarth and Johnson[13] surveyed 128 CGs in Kentucky and identified a range of services, but the need for disease-related information was more pressing than the need for emotional or practical support; the latter need was more highly rated by women and by CGs with greater experience in the caregiving role.

In summary, past studies have identified the needs of community-dwelling rural CGs; however, despite growing recognition of the need to include persons with AD in decisions affecting their care,[14-16] no studies thus far have included their perspective regarding the need for information and services related to their diagnosis. The goal of the current study was to identify and compare the information and service needs of community-dwelling care recipients (CRs) with AD and their CGs living in rural areas.

Methods

Approval for conducting this study was obtained from the Mather LifeWays Institutional Review Board and the Southern Illinois University School of Medicine Springfield Committee for Research Involving Human Subjects. Consent for participation was obtained from CRs and CGs by the interviewer. Study participants were recruited from a dementia-specific clinic in Springfield, Illinois, where CRs were seen for a follow-up visit with a physician. CRs with a prior diagnosis of probable or possible AD using National Institute of Neurologic and Communicative Disorders and Stroke/Alzheimer's Disease and Related Disorders Association criteria[17] and who had Mini-Mental State Examination (MMSE)[18] scores of 10 or greater were eligible to participate. Recent studies have shown that CRs at this level of cognitive impairment are capable of stating their preferences in a reliable and accurate manner.[14,19,20] If a CR were eligible and willing to participate, his or her respective CG was also asked to participate. In this manner, a total of 100 community-dwelling pairs or dyads agreed to participate in this cross-sectional study.

Most CGs were married (86%), whereas a small proportion were separated or divorced (9%) or never married (5%). CGs were primarily white non-Hispanic (97%) and female (61%), and their mean age was 61 years (SD = 13). Education levels were as follows: 38% were high school graduates or completed less education, 29% attended some college, 21% were college graduates, and 12% completed graduate school.

In most cases, the CR was either the CG's spouse (44%) or mother/mother-in-law (36%). The remaining CRs were either the CG's father/father-in-law (10%) or had another relationship with the CG (10%). Most CRs were either married (64%) or widowed (33%), white non-Hispanic (96%), and female (70%), with a mean age of 80 years (SD = 6). Most CRs (64%) had a high school education or less, 24% had some college, 8% were college graduates, and 4% attended graduate school. Most CRs lived with their spouse (41%) or lived alone (37%), with 22% having other living arrangements. The mean MMSE score of CRs was 20.4 (SD = 3.5), indicating a relatively mild degree of cognitive impairment on average. Based on reports by CGs, there was a mean of 37.1 months (SD = 20.7) since AD symptoms were recognized and 24.5 months (SD = 16.7) since the diagnosis of AD had been made by a physician.

The items for the survey were generated from a previous study by one of the authors (D.K.) in which CGs of persons in the early stages of AD (MMSE >19) were interviewed to determine their interest in 16 educational topics and to identify their priorities regarding needs and services.[21] This original list of 16 items was expanded to take into account additional items of interest to CGs caring for relatives with greater cognitive impairment (MMSE score of 10-19). The resulting 22-item Checklist of Interest in Services and Information (hereafter referred to as checklist) included 4 domains: (1) medical needs and interests, 6 items; (2) care needs and interests, 5 items; (3) coping needs and interests, 6 items; and (4) service needs and interests, 3 items (see the appendix for specific items). Two items are not specific to these domains. Both CRs and CGs were asked to rate each item on a 3-point scale (*not interested*, *somewhat interested*, or *very interested*). Interest in an item or topic was defined as a response of *somewhat interested* or *very interested*. To compare CRs' and CGs' responses to the same items, slight adaptations were made in language on 7 of the 21 items to conform to each partner's perspective. Thus, one version was designed for CGs, and another version was designed

Table 1. Top 10 Topics Reported by Caregivers (CGs) and Care Recipients (CRs)

Service/Information	Percentage Somewhat/ Very Interested[a]	
	CGs	CRs
Stages and symptoms of AD	99	70 (1)
Approved drug treatments for ML	99	63 (2)
Alternative medicine or treatments for ML	98	44 (9/10)
Genetic aspects of AD	96	—
Coping with challenging symptoms	96	49 (4/5)
Dealing with family and friends	95	—
Improving communication	95	47 (6/7)
Meaningful activities	92	49 (4/5)
Experimental drugs for ML	89	52 (3)
Coping with my frustration	88	44 (9/10)
Participation in research studies for ML	—	47 (6/7)
Support groups for people with ML	—	45 (8)

Note: ML = memory loss; AD = Alzheimer's disease.

a. Topics are listed in rank order based on CG interest. Number in parentheses indicates the rank order based on CR interest. Topics with the same percentage of interest were assigned 2 rank orders to indicate a tie. A dashed line indicates that the item is not one of the top 10 choices.

for CRs. To ascertain the perspectives of CRs, a clinic staff member interviewed them using the checklist. At the same time, CGs completed their version of the checklist.

Results

Data were analyzed using the Statistical Package for the Social Sciences.[22] Table 1 lists the top 10 service/information topics of interest to both CGs and CRs. Interest in these topics ranged from 99% to 88% for CGs and 70% to 44% for CRs. CGs demonstrated greater interest in each of the topics, but CGs and CRs shared interest in 8 of the top 10 topics. Unique to CGs' top choices were the topics of genetic aspects of AD and dealing with family and friends. Unique to CRs' top choices were the topics of support groups for people with memory loss and participation in research studies for memory loss. The difference between the mean number of topics of interest to CRs and CGs was examined using paired-samples *t* tests. CGs reported interest in significantly ($P < .0005$) more topics ($\bar{x} = 17.9$, SD = 4.3; range, 3-23) than CRs did ($\bar{x} = 8.5$, SD = 5.6; range, 0-21).

Table 2 lists agreement/disagreement between members of each dyad (CGs and CRs). The range of agreement about topics in which both parties were interested was 12% to 70%. The 2 items for which there was the most agreement between CGs and CRs regarding interest in a topic included stages and symptoms of AD (70% agreement) and approved drug treatments for memory loss (63% agreement). The range of agreement, in which both parties were not interested in a topic, ranged from 0% to 50%. CGs and CRs agreed in terms of their lack of interest regarding intimacy and sexuality issues (50% of each group indicated no interest). Total agreement (including both parties who were or were not interested in a topic) ranged from a high of 71% to a low of 32%. Disagreement, in which only CGs were interested in a topic, ranged from 29% to 63%. In more than 58% of the sample, only CGs expressed interest in dealing with family and friends, support groups for caregivers, long-term care, and legal and financial planning. Disagreement, in which only CRs were interested in a topic, ranged from 0% to 10%. Total disagreement ranged from a high of 68% to a low of 29%.

Differences in the mean proportion of items on which CRs and CGs agreed were examined using independent-samples *t* tests. On average, there was agreement on 48% (SD = 23%) of the items. There were no significant differences regarding the mean proportion of items on which there was agreement between CGs who were spouses or adult children, CGs with less than 3 years of experience and CGs with 3 or more years experience, more impaired CRs (MMSE score = 10-19) and less impaired CRs (MMSE score = 20+), female and male CGs, female and male CRs, and CRs who live alone and CRs who live with others.

Differences in the mean number of topics of interest to CGs based on a number of independent variables were examined using independent-samples *t* tests. There were no significant differences in the mean number of topics of interest to CGs based on relationship to CR, MMSE level, CG gender, CR gender, or CR living arrangement. CGs who were providing care for less than 3 years reported an interest in

Table 2. Agreement/Disagreement Within Dyads

	Agree, %		Disagree, %	
Service/Information	Both Interested	Both Not Interested	CGs Interested	CRs Interested
Stages and symptoms of AD	70	1	29	0
Approved drug treatments for ML	63	1	36	0
Meaningful activities	48	7	44	1
Coping with challenging symptoms	48	3	48	1
Experimental drugs for ML	47	6	42	5
Improving communication	46	4	49	1
Participation in research studies for ML	43	10	43	4
Alternative medicine or treatments for ML	42	0	56	2
Coping with my frustration	41	9	47	3
Genetic aspects of AD	40	1	56	3
Coping with my feelings of depression or anxiety	39	11	46	4
Support groups for people with ML	35	9	46	10
Getting information from the Internet	33	19	48	0
Help paying for services	33	13	51	3
Adjusting to increased/decreased responsibilities	33	10	52	5
Dealing with family and friends	32	5	63	0
Decisions about driving	28	20	44	8
Finding services and helpful community resources	27	16	53	4
Support groups for caregivers	22	12	59	7
Long-term care	18	14	61	7
Legal and financial planning	14	20	63	3
Intimacy and sexuality issues	12	50	33	5

Note: CG = caregiver; CR = care recipient; ML = memory loss; AD = Alzheimer's disease.

marginally (*P* = .069) more topics ($\bar{x}$ = 18.6, SD = 3.7) than did CGs who were providing care for 3 or more years ($\bar{x}$ = 17.0, SD = 4.6).

Differences in the mean number of topics of interest to CRs based on a number of independent variables were examined using independent-samples *t* tests. There were no significant differences in the mean number of topics of interest to CRs based on relationship to CG, MMSE level, CG gender, CR living arrangement, and length of time CG had been providing care. Male CRs reported interest in significantly (*P* = .046) more topics ($\bar{x}$ = 10.2, SD = 5.8) than female CRs did ($\bar{x}$ = 7.8, SD = 5.4).

Discussion

Large proportions of CGs in this cross-sectional study expressed a variety of needs, whereas CRs reported fewer needs. More than 90% of all CGs were somewhat or very interested in getting more information regarding stages/symptoms of AD, approved drug treatments, alternative medicine or treatments, and genetic aspects of AD, as well as topics related to day-to-day care of CRs including coping with challenging symptoms, meaningful activities, dealing with family and friends, and improving communication. Overall, results suggest that CGs and CRs had limited knowledge of information and services pertinent to medical aspects of AD and care management issues.

Although fewer CRs than CGs expressed interest in each of the topics, the topics in which the largest proportion of CRs expressed interest were remarkably similar to interests reported by CGs. All of the topics mentioned above for CGs, except for dealing with family and friends, and genetic aspects of AD, were included in CRs' top 10 areas of interests. It is possible that CRs expressed fewer needs than CGs because of apathy, depression, and lack of insight associated with AD, but these explanatory variables were not examined in this study. Nevertheless, several recent studies have shown that CRs with mild and moderate dementia can reliably and consistently report their needs and preferences.[14,19,23,24]

On average, 52% of the dyads disagreed on the items, suggesting substantial disagreement between CGs and CRs in their respective interests for services/information. The need for improved communication is demonstrated by the finding that in 46% of the dyads, both CGs and CRs were interested in finding ways to improve communication. These findings highlight the potential for miscommunication between CGs and CRs and the potential value of promoting dialogue between CGs and CRs about needed services/information.

A large proportion of CGs (95%) expressed interest in dealing with family and friends compared to about a third (32%) of CRs. This may be attributable to CGs' assuming the bulk of the responsibility to interact and communicate with family and friends. Another mismatch between CG and CR perceptions is evidenced by interest in information related to legal/financial planning and long-term care. Whereas more than three quarters of CGs rated these 2 topics to be of interest (77% and 79%, respectively), CRs expressed much lower interest (17% and 25%, respectively). These findings suggest that CRs may underestimate the critical role that CGs play in planning for long-term care needs.

Interestingly, the topic of support groups for people with memory loss was included in CRs' top 10 list but not the CGs' list. In addition, for 10% of the dyads, the CR indicated interest but the CG did not express interest. Although 10% is not a large proportion, this finding illuminates a topic in which the largest proportion of CRs expressed interest when CGs did not. The fact that more than a third of CRs lived alone and may have been socially isolated possibly contributed to their greater interest in participating in a support group.

The difference in relative interest expressed by CRs and CGs is worthy of attention by clinicians interested in enabling both parties to better understand each other and meet their respective needs. For example, many persons with AD are interested in talking with others about their symptoms and learning ways of coping.[25-27] However, their families may not always appreciate this need. The growth of education and support groups for persons with AD sponsored by the Alzheimer's Association and other organizations (largely in urban areas) is a relatively recent phenomenon demonstrating that many CRs wish to talk about living with their disease. Implementing such group programs in rural areas where distance and transportation pose barriers is a vexing challenge that must be addressed in creative ways through collaboration with community partners.[28]

Although the topic in which the greatest disinterest was expressed by both CGs and CRs related to intimacy/sexuality, 45% of CGs expressed interest in this topic. Among CGs who expressed interest in intimacy/sexuality, 74% were spouses. This is clearly a matter of importance for married CGs whose marital relationships are profoundly affected by AD.[29-31]

Few independent variables discriminated among CGs or CRs in terms of the mean number of topics of interest. Marginally significant differences were found based on the length of time of caregiving. CGs with less than 3 years experience expressed an interest in more topics than did CGs with 3 or more years of experience. Perhaps more experienced CGs reported fewer needs because they had had more time to address these needs than less experienced CGs did, or perhaps these needs were no longer relevant to their caregiving situation.

This study illustrates the great need of CGs and CRs for information on a variety of dementia-related topics. Although 2 years on average had elapsed since the diagnosis of AD, both parties still expressed a great desire for basic information and services. Although the issue was not directly addressed in this study, CGs and CRs may have perceived that their need for information and services was not being met by physicians. In a study involving 57 CGs, more than half felt they were not given enough information regarding dementia.[32] A national survey involving 500 primary care physicians and 376 CGs of persons with AD strongly suggests a communication gap between physicians and CGs.[33] In that survey, physicians and CGs often disagreed about what they discussed regarding treatment and caregiving issues at the time of the AD diagnosis. For example, about half of the CGs said they received recommendations from physicians related to caregiving issues, but 97% of physicians said they gave such recommendations. Moreover, only 24% of CGs said they received recommendations about support groups from physicians, but 74% of physicians said they provided such advice to CGs.

Respondents in the current study were attending a follow-up appointment with a physician in a dementia clinic. Therefore, they previously had been informed of the AD diagnosis and presumably were minimally informed about issues related to the disease. Less experienced CGs and CRs are likely to be facing issues similar to those faced by participants in this study and may have even greater needs for information and services related to AD. The needs expressed by study participants hint at the unknown burden borne by rural CGs and CRs in general for information and services that may be critical in coping with the challenges posed by AD.

There were a number of topics in which a large proportion of CGs and CRs shared a mutual interest.

More than 45% of both parties were interested in getting more information regarding stages/symptoms of AD, approved drug treatments, meaningful activities, coping with challenging symptoms, experimental drugs, and improving communication. These most frequently agreed-on needs suggest topics that could be the initial focus of patient and family education. It is also important for clinicians to continually reassess and communicate with persons with AD and CGs to reinforce initial recommendations and address their changing needs. Rather than assuming that a CG understands and represents the need of his or her respective CR, it is also important to be aware that each partner has a unique perspective on coping with the challenges of AD. The needs of both partners must be addressed on an ongoing basis in the clinical setting in light of the progressive nature of the disease. Several studies have described numerous transitions over the course of the caregiving "career."[34-36] The Checklist of Interest in Services and Information used in this study may be a useful tool for clinicians to address the changing needs of CGs and CRs over time.

The present study was limited by its cross-sectional design. A longitudinal study would be helpful to determine how changing needs over time affect interests in information and services of both CGs and CRs. Findings based on this rural sample cannot be generalized to other populations. Further study is necessary to determine if interests expressed by CGs and CRs are similar in urban and more diverse populations. In addition to geographic limitations, respondents were almost exclusive white/non-Hispanic and well educated. Nevertheless, these findings illustrate that educational efforts and service referrals should be targeted to persons with AD and their CGs to suit their respective needs.

Appendix
Checklist Items by Domain

Service/Information	Domain
Meaningful activities	
CR version: Things you're interested in doing	Care
Improving communication	
CR version: Talking with people more easily	Care
Decisions about driving	Care
Help paying for services	Care
Legal and financial planning	Care
Coping with my feelings of depression or anxiety	
CR version: Coping with feeling sad or tense	Coping
Dealing with family and friends	
CR version: Getting along with family and friends	Coping
Coping with challenging symptoms	
CR version: Coping with changes I'm going through	Coping
Adjusting to increased/decreased responsibilities	
CR version: Adjusting to changes in ability to do things for myself	Coping
Coping with my frustration	Coping
Support groups for caregivers	Coping
Genetic aspects of AD	
CR version: Aspects of AD that may be inherited	Medical
Stages and symptoms of AD	Medical
Approved drug treatments for ML	Medical
Alternative medicine or treatments for ML	Medical
Experimental drugs for ML	Medical
Participation in research studies for ML	Medical
Support groups for people with ML	Services
Long-term care	Services
Finding services and helpful community resources	Services
Intimacy and sexuality issues	Stand-alone item
Getting information from the Internet	Stand-alone item

Note: CR = care recipient; AD = Alzheimer's disease; ML = memory loss.

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