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Moon, Heehyul; Rote, Sunshine; Kacmar, Allison; Kostelic, Amy; and Lewis, Bari, "An Exploration of Service Needs and Preferences of Dementia Caregivers in Kentucky" (2022). *Family Sciences Faculty Publications*. 7.

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Digital Object Identifier (DOI)

<https://doi.org/10.34068/joe.60.04.06>

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Recommended Citation

Moon, H., Rote, S., Kacmar, A., Kostelic, A., & Lewis, B. (2022). An Exploration of Service Needs and Preferences of Dementia Caregivers in Kentucky. *The Journal of Extension*, 60(4), Article 6. <https://doi.org/10.34068/joe.60.04.06>

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Cover Page Footnote

Support for this publication was provided by grants from Kent School of Social Work, University of Louisville and Korean American Social Work Educator Association.

An Exploration of Service Needs and Preferences of Dementia Caregivers in Kentucky

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Abstract. As Americans live longer, the prevalence of Alzheimer's disease and related dementias will increase. Caregivers are critical to the care and life quality of people with dementia. Yet, dementia caregivers are at increased risk for health issues, social isolation, and financial challenges. To help educators with the University of Kentucky Cooperative Extension Service work with their local Alzheimer's Association and the University of Louisville to better support dementia families, we explored caregiver needs and service utilization using an online survey. Our findings highlighted the need for counseling/support, care management skills, resource education, self-care strategies, and legal services. Extension Service Educators can use this information to inform program development and support dementia families.

INTRODUCTION

Alzheimer's disease is the most common cause of dementia and the sixth leading cause of death in the United States (Alzheimer's Association, 2022). Approximately 75,000 Kentuckians aged 65 and older live with Alzheimer's disease (Alzheimer's Association, 2020), a number that is projected to rise to 86,000 by 2025—a 15% increase. Many who are living with Alzheimer's disease and related dementia rely on informal caregivers, such as family and friends, for support and care. An estimated 150,000 informal dementia caregivers serve Kentucky families (Alzheimer's Association, 2022). They provide over 265 million hours of unpaid care, with an economic value of over \$3.8 billion (Alzheimer's Association, 2022).

Dementia is one of the illnesses for which care is most expensive due to the long-term 24-hour time demand (Jutkowitz et al., 2017). The typical dementia caregiver is an adult daughter or daughter-in-law who is working full time and balancing caregiving for both an older parent and her own children (Suh, 2016). Her stress is typically higher than non-caregiving and non-dementia caregiving peers due to the financial, emotional, and physical strain of around-the-clock care of a loved one (Karg et al., 2018; Moon, 2016; Moon & Dilworth-Anderson, 2014; Moon et al., 2017). Close to 20% of Kentucky's dementia caregivers report frequent instances of poor mental or physical health (Alzheimer's

Association, 2020). Dementia care services and support can help reduce strain and better aid families providing dementia care, yet little research exists on the topic for dementia caregivers living in Kentucky.

Two important features—geographic location and living arrangements—may shape dementia caregivers' service needs and usage. Kentucky covers 39,728 square miles and hosts an estimated population of 4,467,673 people. While nearly half of Kentucky's counties are rural, only 26.3% of the population live in rural areas (USDA-ERS, 2019). Caregivers in these areas face unique challenges due to rural populations' greater risk for chronic conditions, older average age, difficulty of accessing medical care, limited ability to travel and use technology, lower levels of literacy, and lower socioeconomic status (Foutz et al., 2017; Nichols & Martindale-Adams, 2019; Rahman et al., 2020). Rural caregivers are less likely to utilize formal support services (Gibson et al., 2019), report more time-demanding care situations, and are more likely to report financial barriers and difficulty in providing care than their urban counterparts (Bouldin et al., 2018). This lower use of formal services may be due to a lack of knowledge of available service options as well as a lack of availability of affordable home-based services (Gibson et al., 2019; Innes et al., 2011; Rahman et al., 2020).

Historically, older care recipients living in rural areas are more likely to live with caregivers than those in urban areas. Also, if the family lives far away, they are more likely

to live alone (Rahman et al., 2020). Dementia caregivers who reside with family members living with dementia may need and utilize different support services than those who do not. Caregiver burden is higher among those who co-reside, and service utilization might be greater among those who live apart (Fields et al., 2019; Kerpershoek et al., 2020; Schneider et al., 2002). Rural dementia caregivers who live close to or reside with care recipients have less difficulty attending appointments and coordinating with formal care providers than caregivers who live farther away. Long-distance dementia caregivers are at greater risk of miscommunication and missing information, which can be detrimental to care (Falzarano et al., 2020). Some caregivers run into challenges when their care recipient refuses service (Stephan et al., 2018).

PURPOSE

This study aimed to better understand the relation of geographic location and living arrangements to caregivers' service needs and service delivery preferences (e.g., in-home services, community-based organizations, or technological support) to support the development of intervention strategies for dementia caregivers in Kentucky.

METHOD

SAMPLE

The University of Louisville Kent School of Social Work partnered with the University of Kentucky Cooperative Extension Service and the Greater Kentucky and Southern Indiana Chapter of the Alzheimer's Association to conduct an online statewide survey of dementia caregivers from September 2019 to December 2019. Guided by Pearlin and Skaff's (1998) work on caregiving and the stress process, our survey consisted of six parts: (a) care recipient and caregiver background, (b) primary stressors (such as level of care provided) (c) secondary stressors such as the positive and challenging aspects of care provision, (d) service needs and preferences, (e) resources, including previous experience with and opinions on caregiver support, and (f) effects of care provision on physical and psychological well-being.

With a presence in every county, the University of Kentucky Family Consumer Sciences Extension Service and the Greater Kentucky and Southern Indiana Chapter of the Alzheimer's Association used their networks to disseminate the survey. Information about the survey (e.g., participant eligibility and survey purpose) was advertised in newsletters and newspapers and on social media. To be eligible for the online survey, participants had to be 18 years or older, living in Kentucky, and currently providing care for someone diagnosed with dementia or memory problems. Interested caregivers received an anonymous link to an online survey that took 15-20 minutes to complete. A total of 65 respondents fully

completed the online survey. Out of these respondents, two did not fully complete questions on service use and need; these two surveys were not analyzed, which resulted in a final sample size of 63 dementia caregivers.

MEASURES

Dependent Variable

Service Utilization and Needs. Caregivers were provided with a list of 13 services (see Tables 2 and 3) often utilized by those providing care for someone with dementia. The survey asked caregivers to indicate what services they currently use or have used in the past. Then, questions asked respondents to indicate which services they were not currently utilizing but were interested in learning more about.

Independent Variables

Rural and Urban Counties. The USDA/US Census Bureau (2020) defines *rural* as "all counties outside metropolitan areas" and *urban* as "one or more counties containing a core urban area of 50,000 or more people." Participants provided zip codes which surveyors linked to urban or rural zip codes as defined by the Office of Management and Budget (OMB).

Living Arrangement. Caregivers reported whether or not they lived in the same household as their care recipients at the time of the survey.

Other. Background variables included caregivers' self-reported gender, age, education, race, income, and marital status, as well as the care recipient's age, need for help with activities of daily living (ADLs) (e.g., walking across the room, bathing, personal grooming, eating, getting up from a bed or wheelchair or using a toilet), and relation to the caregiver.

Analysis

In Table 1 we present descriptive statistics of the sample. In Tables 2 and 3 we use chi-square analyses to depict need for and use of formal services by geographic location and living arrangement.

RESULTS

Sample Description

Table 1 presents a description of the sample. Of the 63 respondents, most identified as white (92.1%), were women (88.9%), and were spouses of their care recipients (40%). About 30% were adult children of the care recipient. Caregivers ranged in age from 26 to 85 years old, with an average age of 60. Most caregivers (68%) lived in a rural county, and half co-resided with their care recipient. The average age of dementia care recipients was 78 years old, and over 90% received help from their caregiver with ADLs. Over 40% of the respondents reported dedicating more than 40 hours of care per week.

Service Needs of Dementia Caregivers in Kentucky

There was a significant difference between hours of care given by those who resided with their care recipient and those who did not ($\chi^2_{(1)} = 24.47, p = .001$). Of the caregivers residing with their care recipient, 74% reported providing care over 40 hours per week. Conversely, 88% of caregivers who do not reside with their care recipient reported providing care less than 40 hours per week.

Table 1. Survey Respondent Demographics (N = 63)

Characteristics	Caregivers
Age (M (SD))	60.48 (12.92)
<i>Gender</i>	
Female	88.9%
Male	11.1%
<i>Race</i>	
White	92.1%
Black	1.6%
American Indian/Alaskan Native	1.6%
Mixed Race	1.6%
<i>Income</i>	
34,999 or less	10.7%
35,000–49,999	28.6%
50,000–74,999	25%
75,000 or more	35.7%
<i>Education</i>	
High School or Less	12.7%
Some College	19%
College Degree or More	68.3%
<i>Employment Status</i>	
Full time	39.7%
Part time	6.3%
Unemployed	54%
<i>Living Situation</i>	
Rural County	68.6%
Co-Residing (living with care recipient)	50%
<i>Caregiving in Hours per Week</i>	
Under 40 hours	57.1%
Over 40 hours	42.9%
Care Recipients	
Age (M, (SD))	77.58 (10.43)
ADL Assistance Need	90.5%
<i>Relationship to Caregiver</i>	
Spouse	40%
Adult Child	29.2%
Parent	16.9%
Other	13.8%

Note. ADL refers to Activities of Daily Living.

Service Utilization and Needs

Figure 1 provides a visual representation of caregivers' service utilization and service needs. Table 2 delineates their use of formal services. Approximately half of the caregivers had used support groups (50.8%) or legal services (50.8%) and received education on medication and disease progress (49.1%). Over 25% of caregivers reported having received education on caregiver self-care strategies (28%). Table 2 also shows the use of long-term care facilities (22.8%), adult day care (19.3%), and education on caregiving (19.3%), including hands-on caregiving skills (15.7%) and care management skills (15.7%). We define care management skills as the ability to access health and community-based services. Among caregivers residing with their care recipients, 90% reported having received education on care management skills, and approximately 86% reported having used support groups or counseling. Lastly, 84% of these caregivers reported having used support services related to self-care. Use of these services followed a similar pattern among caregivers who do not reside with the recipient: the majority reported having sought out care management skills (72%), counseling (77%) or support groups (69%), and self-care strategies (68%). We found only one significant difference in service utilization between urban and rural caregivers: a larger percentage of urban caregivers (68%) used support groups than did rural caregivers (57%) ($\chi^2_{(1)} = 5.382, p = .02$). We identified two significant differences in service utilization according to living arrangement. First, 79% ($\chi^2_{(1)} = 15.74, p = .001$) of caregivers living with their care recipients reported using long-term care or nursing home placement. In contrast, only 52% of caregivers not residing with their care recipients reported using long-term care facilities. Second, 75% ($\chi^2_{(1)} = 11.07, p = .001$) of co-residing caregivers reported receiving education in hands-on care, compared to only 68% of non-co-residing caregivers.

Table 3 displays the services in which caregivers expressed interest in learning more about. Most caregivers reported interest in formal services such as counseling (82%), care management skills (81.5%), support groups (78%), education in self-care strategies (77%), hands-on skills (70%), medication and disease progress (70%), and legal services (68%). There were significant differences in service needs for nursing homes or long-term care facilities ($\chi^2_{(1)} = 4.51, p = .034$) and adult daycare ($\chi^2_{(1)} = 6.42, p = .011$) according to living arrangement. Approximately 79% of caregivers who reside with their care recipient were interested in learning more about nursing homes or long-term care facilities, while only 52% of those not living with their care recipient expressed similar interest. Additionally, 72% of caregivers residing with their care recipient were interested in learning more about adult daycare, compared to 38% of caregivers not residing with the recipient.

Table 2. Formal Service Utilization among Caregivers (N = 63)

Type of Services	Currently Use or Have Used (N = 63)	Rural (n = 16)	Urban (n = 35)	Co-Residing (n = 32)	Not Co-Residing (n = 31)
Support Groups for Caregivers	50.8%	57.1%*	67.7%*	85.7%	69.2%
Legal Services	50.8%	57.1%	58%	76.6%	57.6%
Education on Medication and Disease Progress	49.1%	57.1%	41.9%	75%	62.9%
Education in Caregiver Self-care Strategies	28%	50%	22.5%	83.8%	68%
Nursing Homes or LTC Facilities	22.8%	14.2%	25.8%	79.3%***	52%***
Adult Day Care	19.3%	7.1%	25.8%	72.4%	38.4%
Education in Caregiving	19.3%	28.5%	12.9%	64.2%	60%
Education in Hands-on Skills	15.7%	14.2%	12.9%	75%***	68%***
Education in Care-management Skills	15.7%	28.5%	9.6%	89.6%	72%
Education in Use of the Internet	8.7%	0%	6.1%	33.3%	20%
Counseling for Caregivers	7%	0%	12.9%	86.6%	76.9%
Transportation Services	3.5%	7%	0%	46.4%	36%
Grocery Delivery	1.7%	0%	3.2%	42.8%	40%

Note. LTC refers to long-term care. *p < .05, **p < .01, ***p < .001

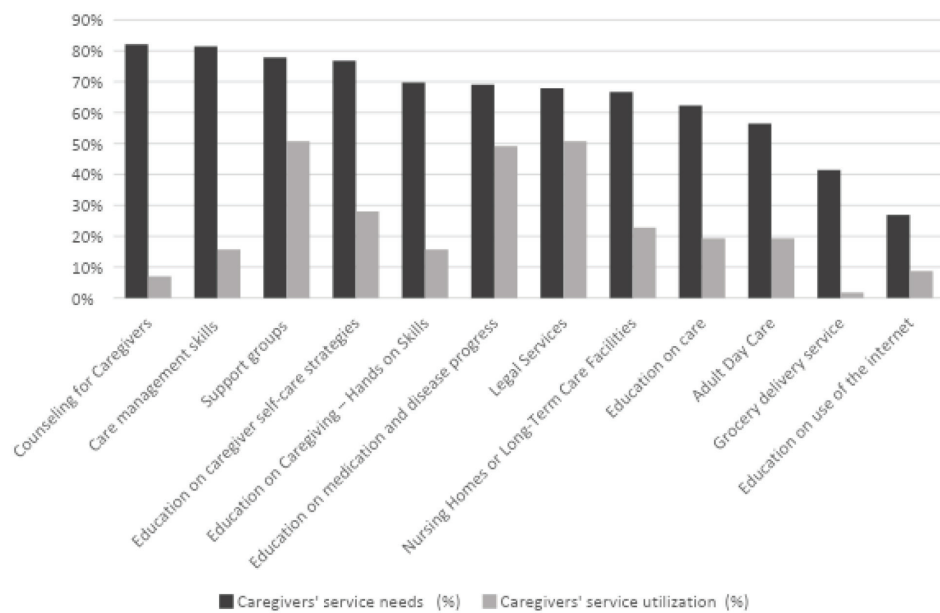


Figure 1. Caregivers' service needs vs. caregivers' service utilization.

Service Needs of Dementia Caregivers in Kentucky

Table 3. Formal Service Needs among Caregivers (N = 63)

Type of Services	Interested Caregivers (N = 63)	Rural (n = 16)	Urban (n = 35)	Co-Residing (n = 32)	Not Co-Residing (n = 31)
Counseling for Caregivers	82.1%	73%	81%	86%	77%
Education in Care-management Skills	81.5%	79%	77%	90%	72%
Support Groups for Caregivers	77.8%	86%	70%	86%	69%
Education in Caregiver Self-care Strategies	76.8%	71%	75%	84%	68%
Education in Hands-on Skills	69.8%	71%	75%	75%	64%
Education on Medication and Disease Progress	69.1%	71%	70%	75%	63%
Legal Services	67.9%	64%	65%	77%	58%
Nursing Homes or LTC Facilities	66.7%	64%	70%	79%*	52%*
Education in Caregiving	62.3%	71%	59%	64%	60%
Adult Day Care	56.4%	43%	65%	72%*	38%*
Transportation Services	41.5%	29%	41%	46%	36%
Grocery Delivery	41.5%	43%	34%	43%	40%
Education in Use of the Internet	26.9%	14%	31%	33%	20%

Note. LTC refers to long-term care. *p < .05, **p < .01, ***p < .001

Practical Implications

Less than half of the respondents reported utilization of formal care services. However, more than two-thirds of dementia caregivers in the current study reported they would like to learn more about most formal service options, particularly counseling, skills training, support groups, and caregiver education. There is also evidence that, except for education on care, transportation services, and education on the use of the Internet, formal service needs are similar regardless of geographic location. Service needs differ more according to living arrangement: for co-residing caregivers, outreach should focus on nursing homes, long-term care facilities, and adult day centers. This difference may be because such care facilities can provide respite that gives caregivers more time to navigate other responsibilities, such as work, family, and self-care. Future planning needs to focus on improved communication regarding services and their availability.

Due to constraints on caregivers' time and abilities to communicate, it will take a cooperative effort to deliver education and care options in a variety of formats, including in-person, online, social media, and print. Telehealth options have worked to overcome some of those barriers. However, barriers to technology include literacy, trust, bandwidth, and access to adequate Internet connection (Prieto et al., 2019).

THE ROLE OF COOPERATIVE EXTENSION SERVICES

County Extension health and wellness educators are trusted community members who understand the social, economic, and environmental determinants of health. Backed by land-grant universities, Extension educators translate and disseminate evidence-based programming in ways that respect individual, family, and community norms, beliefs, and current healthcare practices (Braun et al., 2014). County Extension educators are also able to identify community partners (e.g., the Alzheimer's Association, local health department, area agencies on aging, health providers), engage in resource development such as grant writing and research projects, and support outcomes reporting (e.g., program evaluation). Their local credibility increases the likelihood that they can facilitate change in rural areas. The Extension offices can also be a point of contact for those who have difficulty identifying and/or accessing resources.

Since 2014, Kentucky's Family and Consumer Sciences Extension program has been working with the Greater Kentucky/Southern Indiana Alzheimer's Association chapter. The Alzheimer's Association has trained over 80 county Extension educators to deliver the national curriculum "10 Warning Signs" and "Understanding Alzheimer's Disease

and Dementia.” Extension faculty created lesson evaluations and works with both the Association and county agents to market to and target various audiences, create workshops, and offer learning sessions via multiple delivery platforms. To continue this work during the pandemic, they have created “grab-and-go learning bags” with evidenced-based materials that participants can take home and review on their own time. Extension’s strong local presence and relevant programming leads to sustainable community change and strong partnerships (Braun et al., 2014).

CONCLUSION

Our findings provide additional information on care needs and service utilization among dementia caregivers living in Kentucky. Public service agencies such as Cooperative Extension and the Alzheimer’s Association can use information from this study to make informed decisions on how best to move forward with collaborations, educational resources, and service delivery. For example, the authors can use the results of this study to highlight key areas for development of community support and outreach in Kentucky, particularly counseling and support groups, skills training, and education. Study results also demonstrate that there are significant differences in service needs depending on caregivers’ living arrangements. Those who co-reside are more immediately confronted with their care recipient’s increasing needs for assistance with ADLs and 24-hour care. Thus, they may be in greater need of information on formal care options such as adult daycare, nursing homes, and other LTC facilities and more inclined to proactively gather information to learn about these services (Jutkowitz et al., 2017; Moon & Dilworth-Anderson, 2015).

Use of service differed between urban and rural caregivers; however, we found little difference in the need for services between the two groups, suggesting that outreach to both groups should focus on making services accessible. Greater marketing and availability of all services would be helpful in both rural and urban contexts. Cooperative Extension services, with support from local municipalities, counties, and non-profit organizations, can play important roles in increasing public awareness of dementia and dementia caregiving issues and in supporting tailored outreach strategies to rural and urban caregivers. Intervention strategies should focus on improving access to providers and facilitating service use rather than on providing specific services. This single intervention would help meet the needs of both rural and urban caregivers.

One limitation of this study is the small sample size and lack of educational and racial/ethnic diversity; it does not reflect the entire population of dementia caregivers in Kentucky. There may be caregivers who face more challenges in obtaining and affording formal services. Extension educators

are in a unique position to help the caregivers represented in this study as well and to adapt to meet newly-identified needs of other caregivers. Extension agents will continue to build stronger partnerships with health care professionals and organizations as the population of older adults continues to increase in number and in age. This study illustrates the Cooperative Extension’s potential positive role in improving health and wellness and demonstrates the need for Extension to become more involved with community healthcare partners at the county level.

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