HHS Public Access

Author manuscript

J Okla State Med Assoc. Author manuscript; available in PMC 2022 March 18.

Published in final edited form as:

J Okla State Med Assoc. 2018 November ; 111(9): 836–842.

A population based caregivers profile and training needs assessment in Oklahoma

Janis E. Campbell[1], **Keith Kleszynski**[2], **Amanda E Janitz**[1], **Amber S. Anderson**[1], **Claire Dowers-Nichols**[2], **Andrew N. Dentino**[3], **Laurence Z. Rubenstein**[2], **Thomas A. Teasdale**[1]

[1]Hudson College of Public Health, University of Oklahoma Health Sciences Center, 801 NE 13th St., Oklahoma City, OK, 73104, USA

[2]Donald W. Reynolds Department of Geriatric Medicine, University of Oklahoma Health Sciences Center, 1122 NE 13th St., Oklahoma City, OK, 73117, USA

[3]Graduate Medical Education, School of Medicine, The University of Texas Rio Grande Valley, 5423 S. McColl Road, Edinburg, TX, 78539, USA

Abstract

Background and Objectives—Studies indicate an expected population growth of almost fifty percent in Oklahomans aged 65 and older by 2030. According to the United Health Foundation, Oklahoma ranked 48th in overall senior health in 2017.

Research Design and Methods,—The Oklahoma Healthy Aging Initiative administered a Consumer Needs Assessment Survey by mail to a stratified random sample of the 475,518 registered voters aged 65 and older. The survey was anonymous and stratified by region. The survey contained six sections: introduction, health and health promotion, activities/recreation, information and assistance, caregiving and "about you."

Results—Nearly one in three (32%) of respondents indicated that they directly or indirectly provide care to another, with another 9% responding they *maybe* provide care, and the remaining 59% responding *no*. Nearly 10% of people who say they are not caregivers reported that they participate at least one day a week in caring for a sick or invalid spouse, family member, or friend living with them, indicating current estimates of the number of caregivers is low.

Discussion and Implications—Those who report they *are* or are *maybe* caregivers tend to be more interested in community events and more interested in caregiver respite. In addition, *maybe* caregivers appear to be more interested in health improvement topics and classes, such as health and wellness, mental health, chronic disease, and computers when compared to both caregivers and non-caregivers. Our survey results indicate a need for caregivers to receive respite services as well as training courses in Oklahoma communities.

Keywords

survey; activities and services; stress; recruitment; training

Correspondence: Janis Campbell, PhD, The University of Oklahoma Health Sciences Center, 801 NE 13th Street, Room 309, Oklahoma City, OK 73104, Phone: 1+ 405-271-2229 ext 48062, Fax: 1+ 405-271-2068, janis-campbell@ouhsc.edu.

Conflict of Interest: None

Background and Significance

The 2015 American Community Survey estimated that there were 576,031 individuals aged 65 and older living in Oklahoma and these numbers are expected to increase almost fifty percent to more than 757,000 by 2030.[1,2] At the same time, Oklahoma's health indicators continue to be among the lowest in the US, according to the United Health Foundation, Oklahoma ranked 48th in "overall senior health" in 2017.[3]

Caregiving is a difficult, time-consuming, demanding, yet critical task. Informal caregivers, such as relatives, partners, personal friends, or neighbors, who provide assistance to an adult with a chronic or disabling condition are an important and critical part of the health care system.[4] Overall an estimated 43.5 million people in the US provide informal caregiving services to another. [5] Caregivers have poorer health[6] and reduced quality of life[4,7,8], increased stress[4,6,9–12], increased depression[4,8,11–14], poor sleep[8,11,15], increased stroke or heart disease[15,16], food insecurity[17], diabetes[18], preventive care[19–21], increased obesity[15,22], and increased chronic diseases in general, than non-caregivers.[18,23]

Caregivers' perceptions of service needs, such as caregiver training, health and wellness information and programs, and respite, are important for the planning of such services for their charges as well as for themselves.[24–31] For example, in a 2010 study of perceived caregiver needs for US Veterans in North Carolina, 59% of caregivers stated that they would be interested in a training program. However, significant barriers were identified including transportation, time limitations, their own health limitation, and no perceived need.[27] Among these caregivers there was interest in when and how to ask for help (47%), taking care of themselves (47%), coping with caregiving (41%), and getting respite (41%).[27] This study, however, had a small sample size with only 17 caregivers participating. Another study, of the perceived need of adult care services published in 2014 suggested that while a perceived need may be high at 50%, only 19% of those had used the services.[26]

There have been generally positive but somewhat mixed results of internet and in-person interventions to improve caregiver outcomes, including stress, anxiety, mood, well-being and quality of life.[9,32–45] These interventions often impact the health and wellbeing of the charge.[42,45–47] A recent meta-analysis of interventions to deal with stress, coping among dementia patients and caregiving noted that most systemic reviews of these types of interventions seem to benefit both the caregiver and the charge.[48] However, most discussed general stress and general coping skills rather than specific skills for specific stressors, which would be helpful for those designing interventions.[48]

With the expected senior population growth in the upcoming decades, improving the health and well-being of these caregivers, as well as their charges, is vital to improve the overall health in Oklahoma and the US. The Consumer Needs Assessment Survey was implemented through the Oklahoma Healthy Aging Initiative (OHAI) to determine the perceived needs among Oklahoma's older population. The aim of the OHAI is to improve the health status of older Oklahomans in the next ten years.

One of the goals of the Consumer Needs Assessment Survey was to develop a profile and a needs assessment of older Oklahomans who are serving as caregivers. As discussed above, caregiving is a difficult responsibility and may result in a decline in physical and/or mental health. According to the Administration on Aging, the average age of caregivers caring for someone aged 65 or older is 63 years old, and one-third of these caregivers reported being in fair to poor health.[5] Additionally, in a survey conducted by the National Alliance for Caregiving in 2006, 53% who reported a decline in health as a result of caregiving stated that this decline has impacted their ability to provide care. We believed it was important to determine the needs and training interests unique to this population as well as what makes caregivers unique. Results of this analysis helped guide programming efforts for older Oklahomans serving as caregivers. The goals of the study were to describe older caregivers in Oklahoma and to describe the current activities, interest in future services, classes and activities, perceived barriers to care, and sources of information about health and the community.

Methods

Sample

Data were collected by a mailed survey to a stratified random sample, based on Oklahoma's five OHAI Regions[49], of the 475,518 registered voters aged 65 and older as of January 2013. The survey included name, address, date of birth, and mailing address by county of registration. Using the estimated population counts from the US Census from 2011 and accounting for deceased individuals on the voter registration rolls, we estimated that approximately 85% of all Oklahomans aged 65 and older were represented by these files. A study of voting and registration in the election of November 2012 showed that 87.4% of Oklahomans age 65–74 and 66.5% of Oklahomans age 75 and older were registered to vote.[50]

Instrument-survey information

The survey was anonymous; thus responses were not traceable to any individual, age and ZIP code were requested to allow us to further stratify results by age and region. Each survey packet included an eight-page paper survey and a self-addressed postage paid return envelope. Surveys were mailed on April 23, 2013 (n=6,705). The overall results from this study have been described elsewhere.[49,51]

Questions of Interest

For this study, we wanted to first develop a demographic profile of older caregivers in Oklahoma, and second, current activities, interests in future services, classes and activities, perceived barriers to care, and sources of information about health and the community based on caregiver status. This survey identified older caregivers in Oklahoma based on the question, "Do you ever provide care, either directly or indirectly over the telephone, for someone who is not able to take care of him or herself?"

Demographic information of interest included gender, age, rural/urban location, and OHAI region of residency. Poverty levels were assigned from US Census data and applied to cases

whose postal codes were reported (unknown=98). Each respondent was assigned a category based on their postal code of residence for poverty level, classified as <5%, 5–9%, 10–14%, >15%.

Rural-urban areas were determined from ZIP codes using the four-tier consolidation of the Rural-Urban Commuting Area Codes (RUCA) system (Table 1).[52,53]

Data Analysis

We used a stratified sample weighted by age and region in order to generalize our results to the entire population of Oklahoma aged 65 and older. We used weights that accounted for the probability of being included in the sample by taking the inverse of the proportion of non-response due to returned mail (1/(Returned Mail/Voter Sample Population)). By applying weights to each response we were able to complete statewide estimates. All percentages and 95% confidence intervals (CI) were weighted.

We calculated frequencies, weighted percentages, and weighted standard errors (SE) for the survey questions related to services, classes, and activities that were of interest to Oklahomans aged 65 and older. To determine whether differences were present, we used the Rao-Scott Chi-Square Test, which adjusts for the weighting applied to the survey responses. All analyses were conducted using SAS® 9.4. We assumed an alpha of 0.05 unless otherwise specified.

Human Participants

The study was approved by the University of Oklahoma Health Sciences Center (OUHSC) IRB 1335.

Results

A total of 1,248 surveys were returned and analyzed, resulting in 19.8% response rate. Of those responding to the survey, 1,115 reported their caregiving status (10.7% missing). Of the respondents, more than 1 in 3 older adults (31.5%, standard error [SE]: 1.61) indicated that they directly or indirectly provide care to another, with another 9.1% (SE: 0.97) responding maybe and the remaining 59.3% (SE: 1.69) reporting no ($p<0.0001$). There were no differences by region ($p=0.8649$).

Need for respite care was reported among all caregiver groups. Nearly everyone in each group reported they needed help or more help with their caregiving responsibilities, but there were significant and unexpected differences. Eighty-six percent (85.7%, SE: 2.14) of those who stated *yes* they were caregivers, 91.9% (SE: 2.89) of those that reported they *maybe* caregivers, and 93.1% (SE: 1.31) of those that stated *no* they were not caregivers reported that they needed help or more help with their caregiving responsibilities ($p=0.004$). Finally, 22.9% of those reporting *yes* they were caregivers (SE: 4.87), 18.2% of those reporting they *maybe* caregivers (SE: 2.33), or 12.5% of those reporting *no* they were not caregivers (SE: 1.64) responded that they would be interested in receiving caregiver training ($p=0.02$). We observed no differences in caregiver status by region, gender, age group, rural/urban status, or area poverty level (Table 1).

Current activities and transportation

Regarding current activities that respondents participate in at least one day per week, we observed differences by reported caregiver status in caring for another person living with them (Yes: 26.4%, Maybe: 12.3%, No: 9.1%, p<0.0001), volunteering outside the home (Yes: 35.8%, Maybe: 20.7%, No: 23.3%, p=0.0004), participation in church or religious activities (Yes: 60.0%, Maybe: 73.5%, No: 54.5%, p=0.006), meeting with friends or relatives (Yes: 70.8%, Maybe: 77.7%, No: 62.5%, p=0.006) (data not shown). We also observed differences in the percentage attending a free health event within the last year by caregiver status (Yes: 25.3%, Maybe: 18.7%, No: 16.4%, p=0.01). The only activity that differed by caregiver status was attending a church/faith center (Yes: 43.2%, Maybe: 55.8%, No: 40.2%, p=0.03). Survey respondents were asked mode of transportation and where they spent most of the time when away from home. We observed differences in owning/driving a car (Yes: 95.7%, Maybe: 84.6%, No: 88.9%, p=0.002), having a relative that does not live with them drive (Yes: 3.7%, Maybe: 10.9%, No: 6.1%, p=0.05), and walk/ride a bicycle/ tricycle (Yes: 7.9%, Maybe: 7.8%, No: 4.0%, p=0.05). When asked about their interest in attending a class to help with learning to stay healthy there was a significant difference by caregiver status, with those who are *maybe* caregivers reporting a higher frequency of being somewhat (62.1%) or very interested (26.3%) (p=0.007) (data not shown).

Interest in services, classes and activities

In looking at interest in using specific services, we observed differences by caregiver status for prescription assistance (Yes: 25.1%, Maybe: 37.8%, No: 24.4%, p=0.04) and respite for caregivers (Yes: 13.4%, Maybe: 12.7%, No: 4.3%, p=<0.001). For specific classes, we observed differences for health and wellness (Yes: 34.4%, Maybe: 56.1%, No: 37.4%, p=0.002), mental health (Yes: 11.3%, Maybe: 26.5%, No: 10.7%, p=0.0004), chronic disease management (Yes: 15.7%, Maybe: 12.8%, No: 9.1%, p=0.02), caregiver (Yes:12.5%, Maybe: 13.9%, No: 5.0%, p=0.0002), and computer/internet classes (Yes: 44.2%, Maybe: 50.6%, No: 37.3%, p=0.03). For specific activities, there were differences by caregiver status for dance/dance lessons (Yes: 19.6%, Maybe: 19.9%, No: 12.6%, p=0.02) and other, unspecified activities (Yes: 1.50%, Maybe: 14.1%, No: 6.1%, p=0.04). Perceived barriers to accessing services by caregiver status indicate differences in transportation (Yes: 6.1%, Maybe: 19.2%, No: 5.6%, p=0.04) and “Just don’t want to go” (Yes: 24.6%, Maybe: 12.3%, No: 33.1%, p<0.0001).

Sources of Information

We observed differences in sources of information about help for older adults or community events by caregiver status for aging agencies/senior centers/retirement communities (Yes: 20.2%, Maybe: 18.8%, No: 13.7%, p=0.05), church (Yes: 34.1%, Maybe: 41.9%, No: 27.4%, p=0.01) and community organizations (Yes: 16.5%, Maybe: 20.9%, No: 9.9%, p=0.004) (data not shown). Regarding services in the community, church/faith-based organizations (Yes: 51.2%, Maybe: 62.1%, No: 40.8%, p=0.0003); family, neighbors, or friends (Yes: 72.5%, Maybe: 76.0%, No: 62.9%, p=0.007); newsletters, flyers, or bulletins (Yes: 48.1%, Maybe: 42.3%, No: 38.7%, p=0.04); newspapers (Yes: 77.0%, Maybe: 70.4%,

No: 67.2%, p=0.02); and radio (Yes: 30.3%, Maybe: 31.4%, No: 19.6%, p=0.001) differed by caregiver status.

Discussion and Implications

We estimate there are about 160,617 older Oklahomans that are caregivers. We do not see any demographic differences in caregiver status in the population in Oklahoma. In particular, there are men and women in all age groups and in all regions of the state that provide care and there are caregivers in high and low poverty areas. Additionally, nearly 10% of people who say they are not caregivers report that they participate at least one day a week in caring for a sick or invalid spouse, family member, or friend living with them. Thus, these estimates are undoubtedly low. Approximately 20% of older caregivers reported they would be interested in receiving caregiver training, therefore offering free or reduced-cost caregiver training to older Oklahoma caregivers may be beneficial.

Perhaps the most important finding from this study is that there are differences based on caregiver status. There are suggestive trends depending on if someone who reports themselves as *yes* a caregiver, *maybe* a caregiver, or *no* not a caregiver. Those who report they are not a caregiver tend to be less interested in community and health promotion events. This can be seen by their lower levels of attendance at church or religious activities, meetings with friends, attendance at health event events, and their lower reported interest in attending events to keep themselves healthy. Moreover the increased percentage of responding they "*just don't want to go*" as a barrier to accessing programs indicates those who do not consider themselves caregivers have decreased interest in events involving groups of people.

Those who report they are or maybe caregivers tend to be more interested in community events and are more interested in caregiver respite as well as training. However, they don't attend church or religious activities as much as those who *maybe* caregivers. We believe that many caregivers may not have the time for a lot of other community activities such as church and health assessment. However, this group is also the most likely to volunteer to work outside the home. Interestingly, caregivers also appear to be more interested in health improvement topics and classes, such as health and wellness, mental health, chronic disease, and computers when compared to non-caregivers.

Among those who report that they *maybe* caregivers there are some interesting trends. Interestingly, *maybe* caregivers appear to be more interested in health improvement topics and classes, such as health and wellness, mental health, chronic disease, and computers when compared to both caregivers and non-caregivers. This group is the most likely to report attendance at church or meeting with friends as something they participate in at least one day a week and they attend church during most of their time away from home. They are also the most interested in prescription assistance, classes focused on health and wellness, mental health, using the computer/Internet, and participating in dance/dance lessons and other unspecified activities. Finally they are most likely to report getting information from churches or community organizations. Because it is not clear from the survey how much time the *maybe* providers were providing care, we plan to incorporate this into

future surveys. We believe that these individuals might be still early on in the caregiving experience, with more time for classes and activities than those reporting they are caregivers and appear to be a group who may be receptive to caregiver training.

As stated previously, caregivers have poorer health[6] and reduced quality of life[4,7,8], increased stress[4,6,9–12], increased depression[4,8,11–14], poor sleep[8,11,15], stroke or heart disease[15,16], food insecurity[17], diabetes[18], preventive care[19–21], increased obesity[15,22], other chronic diseases.[18,23] We know that even when services are seen as beneficial they may not be used by those in greatest need.[27] Finally, we know that there have been effective interventions to improve caregiver outcomes, including stress, anxiety, mood, wellbeing and quality of life.[9,32–45] These interventions often impact the health and wellbeing of the charge.[42,45–47] Knowing something about the perceived need, including what caregivers in Oklahoma are currently doing and where they get their information, is an important step to reducing this growing burden.

Strengths and limitations

Limitations of this study include the use of voter registry as a population source and the low response rate. Participants were selected from the Oklahoma Voter Registration file and the estimated voter registration differed by age group (87.4% for ages 65–74 and 66.5% for age 75 and older). Consequently, results of this survey may not be representative of the entire Oklahoma senior population, in particular those not eligible to vote and those less likely to register to vote despite eligibility. This latter group is likely to be less socially engaged and at increased risk for poor health. Differences in interests and barriers to program access likely exist between those who responded and those who did not. There is a potential for information bias due to survey fatigue or unclear questions, for example the question about caregiver status. Because so many of the respondents who reported they were either maybe or not caregivers, we plan to explore this question structure further. However, it may also indicate differing levels of caregiving status (future, early, current caregivers) and help identify caregiving needs for older adults.

Strengths of this survey include the large sample size that allows for understanding of differences between and among groups. Although a limitation since the survey population was restricted to registered voters in Oklahoma, a strength of this sampling strategy is that voters are a large proportion of the state (85% as reported by the US Census for 2012).[50] In addition, our stratified sample methodology and weighting of the data was a strength that allows our results to be representative of the entire state. Finally, our inclusion of *maybe* as a potential response to the question of “Do you ever provide care, either directly or indirectly over the telephone, for someone who is not able to take care of him or herself?” adds a distinctive group that we are now considering as a potential target group for interventions.

Conclusion

Results from the study provided a profile and needs assessment of Oklahoma seniors who are serving as caregivers. Programming efforts for seniors serving as caregivers should focus on providing respite services and offering training courses in Oklahoma communities. While we do not have unlimited resources we recognize that caregivers come in all social

and demographic groups and that most do feel they need help. In addition, while sources to get information to older Oklahoman caregivers appears to be mainly newspapers, other important sources such as friends, family and religious centers should also be used.

Acknowledgments

Funding: JC, TT, CN, KK, AD, and LR were partially supported by a grant from the Donald W. Reynolds Foundation. The content is solely the responsibility of the authors and does not necessarily represent the official views of the DWR. AA was partially supported by sub award number RS201340494–14 from the Oklahoma Shared Clinical and Translational Resources. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

References

1. United States Department of Health and Human Services. Administration on Aging (AoA): Project Future Growth of the Older Population. 2015; http://www.aoa.acl.gov/Aging_Statistics/future_growth/future_growth.aspx. Accessed March 24, 2015.
2. United States Census Bureau. U.S. Census Bureau, 2015 American Community Survey. 2017; http://factfinder.census.gov/. Accessed February 13, 2015
3. United Health Foundation. America's Health Rankings Senior Report: A Call to Action for Individuals and Their Communities. In: 2017 ed. Minnetonka, MN: United Health Foundation; 2017: http://www.americashealthrankings.org/learn/reports/2017-senior-report. Accessed March 8, 2018.
4. Evercare NAfC. Study of Caregivers in Decline: Findings from a National Survey. Bethesda, MD: National Alliance for Caregiving;2006.
5. Family Cargiver Alliance NCoC. Caregiver Statistics: Demographics. [Webpage]. 2017; https://www.caregiver.org/caregiver-statistics-demographics. Accessed 08/25/2017, 2017.
6. Anderson LA, Edwards VJ, Pearson WS, Talley RC, McGuire LC, Andresen EM. Adult caregivers in the United States: characteristics and differences in well-being, by caregiver age and caregiving status. Prev Chronic Dis. 2013;10:E135.
7. Edwards VJ, Anderson LA, Thompson WW, Deokar AJ. Mental health differences between men and women caregivers, BRFSS 2009. J Women Aging. 2017;29(5):385–391. [PubMed: 27759499]
8. Trivedi R, Beaver K, Bouldin ED, et al. Characteristics and well-being of informal caregivers: Results from a nationally-representative US survey. Chronic Illn. 2014;10(3):167–179. [PubMed: 24154869]
9. Camak DJ. Addressing the burden of stroke caregivers: a literature review. J Clin Nurs. 2015;24(17–18):2376–2382. [PubMed: 26095074]
10. Fonareva I, Oken BS. Physiological and functional consequences of caregiving for relatives with dementia. Int Psychogeriatr. 2014;26(5):725–747. [PubMed: 24507463]
11. Lavela SL, Etingen B, Louise-Bender Pape T. Caregiving experiences and health conditions of women veteran and non-veteran caregivers. Womens Health Issues. 2013;23(4):e225–232. [PubMed: 23816152]
12. Gaugler JE. The longitudinal ramifications of stroke caregiving: a systematic review. Rehabil Psychol. 2010;55(2):108–125. [PubMed: 20496966]
13. Wise J Depression links to physical health decline in cancer caregivers. Bmj-Brit Med J. 2017;357:j3160.
14. Romero-Martinez A, Ruiz-Robledillo N, Moya-Albiol L. Depressive Mood and Testosterone Related to Declarative Verbal Memory Decline in Middle-Aged Caregivers of Children with Eating Disorders. Int J Environ Res Public Health. 2016;13(3).
15. LaVela SL, Landers K, Etingen B, Karalius VP, Miskevics S. Factors related to caregiving for individuals with spinal cord injury compared to caregiving for individuals with other neurologic conditions. J Spinal Cord Med. 2015;38(4):505–514. [PubMed: 24993244]

16. Johnson TV, Abbasi A, Master VA. Systematic review of the evidence of a relationship between chronic psychosocial stress and C-reactive protein. Mol Diagn Ther. 2013;17(3):147–164. [PubMed: 23615944]
17. Horner-Johnson W, Dobbertin K, Kulkarni-Rajasekhara S, Beilstein-Wedel E, Andresen EM. Food Insecurity, Hunger, and Obesity Among Informal Caregivers. Prev Chronic Dis. 2015;12:E170.
18. Lovell B, Wetherell MA. The cost of caregiving: endocrine and immune implications in elderly and non elderly caregivers. Neurosci Biobehav Rev. 2011;35(6):1342–1352. [PubMed: 21333674]
19. Reeves KW, Bacon K, Fredman L. Caregiving associated with selected cancer risk behaviors and screening utilization among women: cross-sectional results of the 2009 BRFSS. BMC Public Health. 2012;12:685. [PubMed: 22908937]
20. Jamoom EW, Andresen EM, Neugaard B, McKune SL. The effect of caregiving on preventive care for people with disabilities. Disabil Health J. 2008;1(1):51–57. [PubMed: 21122711]
21. Thorpe JM, Sleath BL, Thorpe CT, et al. Caregiver psychological distress as a barrier to influenza vaccination among community-dwelling elderly with dementia. Med Care. 2006;44(8):713–721. [PubMed: 16862032]
22. Wardle J, Chida Y, Gibson EL, Whitaker KL, Steptoe A. Stress and adiposity: a meta-analysis of longitudinal studies. Obesity (Silver Spring). 2011;19(4):771–778. [PubMed: 20948519]
23. Pearson WS, Bhat-Schelbert K, Probst JC. Multiple chronic conditions and the aging of america: challenge for primary care physicians. J Prim Care Community Health. 2012;3(1):51–56. [PubMed: 23804855]
24. Liu C, Eom K, Matchar DB, Chong WF, Chan AW. Community-Based Long-Term Care Services: If We Build It, Will They Come? J Aging Health. 2016;28(2):307–323. [PubMed: 26129700]
25. Miller KM, Kabat M, Henius J, Harold C, Van Houtven H. Engaging, Supporting, and Sustaining the Invisible Partners in Care: Young Caregivers of Veterans From the Post-9/11 Era. N C Med J. 2015;76(5):320–322. [PubMed: 26946865]
26. Brown EL, Friedemann ML, Mauro AC. Use of adult day care service centers in an ethnically diverse sample of older adults. Journal of applied gerontology : the official journal of the Southern Gerontological Society. 2014;33(2):189–206. [PubMed: 24652954]
27. Van Houtven CH, Oddone EZ, Weinberger M. Informal and formal care infrastructure and perceived need for caregiver training for frail US veterans referred to home and community-based services. Chronic Illn. 2010;6(1):57–66. [PubMed: 20308351]
28. Tang F, Lee Y. Home- and community-based services utilization and aging in place. Home health care services quarterly. 2010;29(3):138–154. [PubMed: 20845175]
29. Hong SI. Understanding patterns of service utilization among informal caregivers of community older adults. Gerontologist. 2010;50(1):87–99. [PubMed: 19574540]
30. Beeber AS, Thorpe JM, Clipp EC. Community-based service use by elders with dementia and their caregivers: a latent class analysis. Nurs Res. 2008;57(5):312–321. [PubMed: 18794715]
31. Ploeg J, Biehler L, Willison K, Hutchison B, Blythe J. Perceived support needs of family caregivers and implications for a telephone support service. Can J Nurs Res. 2001;33(2):43–61. [PubMed: 11928335]
32. Liddle J, Liang P. Mixed evidence exists for Internet-based education and support interventions for caregivers of someone with a chronic health condition in enhancing wellbeing and decreasing stress. Aust Occup Ther J. 2016;63(2):137–138. [PubMed: 27045531]
33. Aldehaim AY, Alotaibi FF, Uphold CR, Dang S. The Impact of Technology-Based Interventions on Informal Caregivers of Stroke Survivors: A Systematic Review. Telemed J E Health. 2016;22(3):223–231. [PubMed: 26274910]
34. Lee E Do Technology-Based Support Groups Reduce Care Burden Among Dementia Caregivers? A Review. J Evid Inf Soc Work. 2015;12(5):474–487. [PubMed: 25794367]
35. Hu C, Kung S, Rummans TA, Clark MM, Lapid MI. Reducing caregiver stress with internet-based interventions: a systematic review of open-label and randomized controlled trials. J Am Med Inform Assoc. 2015;22(e1):e194–209. [PubMed: 25125686]
36. Razani J, Corona R, Quilici J, et al. The Effects of Declining Functional Abilities in Dementia Patients and Increases Psychological Distress on Caregiver Burden Over a One-Year Period. Clin Gerontol. 2014;37(3):235–252. [PubMed: 24839349]

37. Harrison F, Low LF, Barnett A, Gresham M, Brodaty H. What do clients expect of community care and what are their needs? The Community care for the Elderly: Needs and Service Use Study (CENSUS). Australasian journal on ageing. 2014;33(3):206–213. [PubMed: 24372663]
38. Bakas T, Clark PC, Kelly-Hayes M, et al. Evidence for stroke family caregiver and dyad interventions: a statement for healthcare professionals from the American Heart Association and American Stroke Association. Stroke. 2014;45(9):2836–2852. [PubMed: 25034718]
39. Seeher K, Low LF, Reppermund S, Brodaty H. Predictors and outcomes for caregivers of people with mild cognitive impairment: a systematic literature review. Alzheimers Dement. 2013;9(3):346–355. [PubMed: 23123229]
40. Sansoni J, Anderson KH, Varona LM, Varela G. Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some considerations on existing literature. Ann Ig. 2013;25(3):235–246. [PubMed: 23598807]
41. Loupis YM, Faux SG. Family conferences in stroke rehabilitation: a literature review. J Stroke Cerebrovasc Dis. 2013;22(6):883–893. [PubMed: 23352687]
42. Northouse L, Williams AL, Given B, McCorkle R. Psychosocial care for family caregivers of patients with cancer. J Clin Oncol. 2012;30(11):1227–1234. [PubMed: 22412124]
43. LaVela SL, Johnson BW, Miskevics S, Weaver FM. Impact of a multicomponent support services program on informal caregivers of adults aging with disabilities. Journal of gerontological social work. 2012;55(2):160–174. [PubMed: 22324332]
44. Abdulraheem IS, Parakoyi DB. Improving attitude towards elderly people: Evaluation of an intervention programme for caregivers. Niger Postgrad Med J. 2005;12(4):280–285. [PubMed: 16380740]
45. Van Houtven CH, Voils CI, Weinberger M. An organizing framework for informal caregiver interventions: detailing caregiving activities and caregiver and care recipient outcomes to optimize evaluation efforts. BMC Geriatr. 2011;11:77. [PubMed: 22107600]
46. Tschanz JT, Piercy K, Corcoran CD, et al. Caregiver coping strategies predict cognitive and functional decline in dementia: the Cache County Dementia Progression Study. Am J Geriatr Psychiatry. 2013;21(1):57–66. [PubMed: 23290203]
47. Norton MC, Clark C, Fauth EB, et al. Caregiver personality predicts rate of cognitive decline in a community sample of persons with Alzheimer's disease. The Cache County Dementia Progression Study. Int Psychogeriatr. 2013;25(10):1629–1637. [PubMed: 23830578]
48. Gilhooly KJ, Gilhooly ML, Sullivan MP, et al. A meta-review of stress, coping and interventions in dementia and dementia caregiving. BMC Geriatr. 2016;16:106. [PubMed: 27193287]
49. Campbell JE, Janitz AE, Teasdale TA, et al. Assessing Statewide Need for Older Adult Health Promotion Services: The Oklahoma Experience. Journal of Social Service Research. 2018;44(2):119–131. [PubMed: 31592202]
50. United States Census Bureau. Voting and Registration in the Election of November 2012 - Detailed Tables. 2013; https://www.census.gov/hhes/www/socdemo/voting/publications/p20/2012/tables.html. Accessed March 24, 2015, 2016.
51. Campbell JE, Janitz AE, Kleszynski K, et al. Results from the 2013 Senior's Health Services Survey: Rural and Urban Differences. Journal of Community & Public Health Nursing. 2018;04(02).
52. United States Department of Agriculture. Measuring Rurality: Rural-Urban Continuum Codes. [web page]. 2004; http://webarchives.cdlib.org/sw1wp9v27r/http:/ers.usda.gov/Briefing/Rurality/RuralUrbCon/. Accessed October 7, 2015.
53. WWAMI Rural Health Research Center. RUCA Data: Zip Code RUCA Approximation. 2015; http://depts.washington.edu/uwruca/ruca-approx.php. Accessed October 9, 2015.

J Okla State Med Assoc. Author manuscript; available in PMC 2022 March 18.

Table 1:

Caregiver status by demographics characteristics Oklahoma 2013

	Yes			Maybe			No			p-value
	N	%	SE	N	%	SE	N	%	SE	
Region										0.86
Central	81	30.8	2.85	21	8.0	1.67	161	61.2	3.01	
Northeast	76	33.5	3.14	20	8.8	1.89	131	57.7	3.29	
Northwest	67	31.8	3.21	24	11.4	2.19	120	56.9	3.42	
Southeast	59	28.0	3.10	22	10.4	2.11	130	61.6	3.36	
Southwest	64	31.5	3.27	22	10.8	2.19	117	57.6	3.48	
Gender										0.58
Male	111	29.5	2.70	37	8.7	1.60	231	61.9	2.86	
Female	234	32.4	2.00	72	9.4	1.23	427	58.2	2.10	
Age Group										0.71
64–74	204	30.8	2.04	62	8.9	1.28	398	60.2	2.16	
75–84	121	34.4	2.92	34	8.0	1.57	203	57.6	3.03	
85+	22	26.3	5.59	13	14.4	3.85	58	59.3	5.99	
Rural/Urban Status										0.29
Urban Core[a]	98	31.3	2.68	24	7.7	1.68	191	61.0	2.85	
Sub-Urban[b]	27	25.7	4.67	13	12.4	3.44	65	61.9	5.13	
Large Rural Town[c]	98	30.5	3.09	32	10.0	1.71	191	59.5	3.25	
Small Town/Isolated[d]	124	33.0	3.03	40	10.6	1.75	212	56.4	3.07	
Area Poverty Level										0.43
<5%	49	29.7	3.74	17	9.9	2.45	97	60.4	4.02	
5–9%	135	28.9	2.46	51	9.2	1.49	284	61.9	2.62	
10–14%	102	35.4	3.18	24	7.3	1.69	176	57.3	3.26	
15%+	55	35.1	4.34	17	12.4	3.07	95	52.5	4.49	

[a]Contiguous built-up areas of 50,000 persons or more;

[b]Sub-Urban Metropolitan Counties, with high commuting flows to urban cores;

[c] Populations between 10,000 and 49,999 and surrounding rural areas with 10% or more primary commuting flows to these towns, as well as secondary commuting flows of 10% or more to urban cores;

[d] Populations below 10,000 and their surrounding commuter areas and other isolated rural areas with more than one hour driving distance to a nearest city

Table 2:

Interest in services, classes, and activities and perceived barriers to accessing programs among Oklahomans aged 65 and older by caregiver status: Oklahoma 2013

	Yes			Maybe			No			p-value
	N	%	SE	N	%	SE	N	%	SE	
Services										
Legal assistance (wills, power of attorney, medical powers of attorney, etc)	194	57.5	3.06	57	49.9	5.59	330	49.9	2.25	0.12
Assistance with tax preparation	112	33.5	2.94	31	29.0	5.09	199	30.2	2.06	0.60
Telephone reassurance (daily check-in calls)	25	6.9	1.52	13	11.4	3.44	50	8.2	1.27	0.42
Congregate meals at a center	38	9.8	1.80	19	18.2	4.34	68	9.6	1.30	0.06
Home delivered meals	29	9.0	1.79	9	11.2	3.80	64	9.1	1.28	0.84
Health screenings	139	40.0	3.01	49	38.2	5.21	225	34.0	2.12	0.23
Prescription assistance	**92**	**25.1**	**2.67**	**41**	**37.8**	**5.38**	**165**	**24.4**	**1.92**	**0.04**
Respite for caregivers	**41**	**13.4**	**2.14**	**13**	**12.7**	**3.77**	**28**	**4.3**	**0.92**	**<0.0001**
Other	23	8.1	1.79	13	10.4	3.24	42	6.9	1.14	0.53
Classes										
Health and wellness	**118**	**34.4**	**2.95**	**59**	**56.1**	**5.56**	**241**	**37.4**	**2.18**	**0.002**
Cooking	70	19.3	2.44	22	22.4	4.70	116	18.0	1.73	0.64
Nutrition	94	29.1	2.85	35	37.3	5.50	158	25.4	1.97	0.08
Exercise	164	48.7	3.10	46	46.2	5.62	255	40.5	2.21	0.08
Mental Health	**42**	**11.3**	**1.91**	**24**	**26.5**	**5.08**	**70**	**10.7**	**1.40**	**0.0004**
Chronic Disease	**53**	**15.7**	**2.25**	**17**	**12.8**	**3.45**	**61**	**9.1**	**1.30**	**0.02**
Caregiver	**41**	**12.5**	**2.04**	**12**	**13.9**	**4.02**	**35**	**5.0**	**0.96**	**0.0002**
Using the computer and/or Internet	**156**	**44.2**	**3.08**	**52**	**50.6**	**5.59**	**249**	**37.3**	**2.17**	**0.03**
Arts and crafts/hobby	116	33.6	2.93	36	36.9	5.50	171	27.0	2.00	0.07
Storm preparedness (Tornado, Ice etc…)	46	10.2	1.69	20	16.6	3.99	81	12.5	1.49	0.26
Other (please specify)	16	5.2	1.41	5	7.0	3.19	31	5.0	0.98	0.79
Activities										
Indoor exercise activities	166	48.4	3.10	51	46.7	5.59	281	44.7	2.24	0.61
Outdoor exercise activities	101	31.0	2.88	26	22.7	4.62	150	24.5	1.96	0.11
Walking classes, supervised walking, walking trails	112	34.1	2.94	33	32.4	5.31	201	31.5	2.10	0.77

	Yes			Maybe			No			p-value
	N	%	SE	N	%	SE	N	%	SE	
Card, board, and table games (bridge, poker, dominoes, scrabble, bingo etc.)	89	26.5	2.76	30	25.7	4.84	138	21.1	1.84	0.21
Day trips (such as to museums, parks)	142	39.1	3.00	50	46.6	5.60	253	38.5	2.19	0.40
Dances or dance lessons	**63**	**19.6**	**2.51**	**20**	**19.9**	**4.53**	**77**	**12.6**	**1.53**	**0.02**
Nature-related activities	85	24.7	2.64	29	29.5	5.18	132	20.8	1.84	0.16
Billiards, Shuffleboard, Ping Pong	28	9.6	1.90	9	5.7	2.07	43	6.9	1.15	0.25
Croquet, lawn polo, horseshoes Tennis, basketball, volleyball	33	10.9	1.96	13	14.3	4.11	45	7.1	1.16	0.06
Other	**21**	**6.3**	**1.50**	**12**	**14.1**	**4.19**	**38**	**6.1**	**1.09**	**0.04**
Perceived barriers to accessing programs										
Transportation	**17**	**6.1**	**1.62**	**15**	**19.2**	**4.95**	**28**	**5.6**	**1.15**	**0.04**
Location	62	18.1	2.45	20	21.5	4.87	107	18.6	1.85	0.82
Lack of adequate facilities	47	12.9	2.09	16	17.3	4.48	73	11.9	1.50	0.51
Didn’t know about services	62	20.0	2.60	24	25.8	5.18	124	22.7	2.02	0.54
Don’t know how to access/enroll in services	23	7.1	1.68	12	15.2	4.56	36	6.7	1.21	0.22
Just don’t want to go	**68**	**24.6**	**2.89**	**14**	**12.3**	**3.61**	**199**	**33.1**	**2.23**	**<0.0001**
Other	70	24.7	2.88	19	21.4	5.07	104	18.4	1.87	0.18