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Financial and Health Barriers and Caregiving-Related Difficulties among Rural and Urban Caregivers

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Abstract

Purpose—To assess whether financial or health-related barriers were more common among rural caregivers and whether rural caregivers experienced more caregiving-related difficulties than their urban peers.

Methods—We used data from 7,436 respondents to the Caregiver Module in 10 states from the 2011-2013 Behavioral Risk Factor Surveillance System. Respondents were classified as caregivers if they reported providing care to a family member or friend because of a long-term illness or disability. We classified respondents as living in a rural area if they lived outside of a Metropolitan Statistical Area (MSA). We defined a financial barrier as having an annual household income < \$25,000 or not being able see a doctor when needed in the past year because of cost. We defined a health barrier as having multiple chronic health conditions, a disability, or fair or poor self-rated health.

Findings—Rural caregivers more frequently had financial barriers than urban caregivers (38.1% versus 31.0%, $p=0.0001$), but the prevalence of health barriers was similar (43.3% versus 40.6%, $p=0.18$). After adjusting for demographic differences, financial barriers remained more common among rural caregivers. Rural caregivers were less likely than their urban peers to report that caregiving created any difficulty in both unadjusted and adjusted models (adjusted prevalence ratio [PR]=0.90; $p<0.001$).

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Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Disclosure

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Conclusions—Informal caregivers, particularly in rural areas, face financial barriers. Rural caregivers were less likely than urban caregivers to report caregiving-related difficulties. Rural caregivers' coping strategies or skills in identifying informal supports may explain this difference, but additional research is needed to explore this hypothesis.

Keywords

caregiving; rural; financial strain; health status

Introduction

Informal care provided by friends and family members of people with chronic health conditions or disability is a vital component of the United States long-term care system.¹ These caregivers provide a variety of types of support including taking care recipients to medical appointments, helping them manage diet and medications at home, and dressing and facilitating their participation in social activities.^{2–6} Having informal support available can help people who need care remain in the community longer and better manage their self-care.⁵ Informal caregivers may experience benefits as a result of providing care, such as feeling closer to the care recipient, but they also may encounter strains like having less time to care for themselves and their children or incurring costs as a result of providing support to someone with a chronic health condition or disability.^{1,3,7–9}

In rural areas of the US, adults with chronic conditions and disabilities face more barriers to accessing health care. For example, there often are fewer long-term support services like nursing care available in rural areas and rural areas also may lack health care services like rehabilitation care.^{10–13} Therefore, the demand for informal care may be greater in rural areas than in urban areas because family and friends may need to fill these gaps by providing community-based care.

The higher prevalence of chronic conditions and disabilities in rural areas also may mean that caregivers in rural areas themselves have a higher burden of poor health than caregivers living in urban areas.¹⁴ Caregivers with chronic conditions may experience greater burdens associated with caregiving because caregiving may negatively impact health through increased stress or physical demands.¹⁵ Providing care also may result in caregivers having less time to care for their own health needs.

Caregivers living in rural areas also face financial challenges. In general, rural Americans have lower incomes than their urban peers.¹⁴ Furthermore, there is evidence that workplaces in rural areas can be more challenging both in terms of the potential for work-related injuries and for difficulty in taking time off of work to care for a family member or friend.^{14,16}

Our aims were to assess whether financial or health-related barriers varied among caregivers by place of residence, and determine whether rural caregivers were more likely to report difficulties associated with caregiving than their urban peers.

Methods

Data Source

The Caregiver Module is a set of 10 questions that was developed for the Behavioral Risk Factor Surveillance System (BRFSS), an annual telephone survey of community dwelling US adults age 18 and older.¹⁷ The module was cognitively tested – i.e., underwent systematic evaluation to assure respondents understood the questions – and has been included as an optional BRFSS module in previous years with support from the Healthy Aging Program at the Centers for Disease Control and Prevention (CDC).^{3,18} We used data from the 10 states that included the Caregiver Module as state-added questions in 2011 (New Jersey), 2012 (Indiana, Iowa, Maine, Mississippi, Missouri, West Virginia, and Wisconsin), or 2013 (Arkansas and Illinois) and could provide the Metropolitan Statistical Area to enable us to classify respondents as living in a rural or urban area. This study was reviewed by the Appalachian State University IRB and classified as exempt (IRB 17-0012).

Caregiver Status

We classified respondents as caregivers if they said “yes” to the Caregiver Module screening question: “People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?” We classified respondents who said “no” to the caregiver screening question as non-caregivers.

Of the 50,306 respondents who were asked the caregiver screening question, 10,390 (19.6% weighted) were caregivers and 8,378 (81%) had non-missing MSA codes, enabling us to classify them as rural or urban caregivers. We excluded 942 caregivers who were missing information on vital covariates, leaving 7,436 (72% of all caregivers and 89% of rural/urban caregivers) in this study.

Caregiving Characteristics and Experience

Respondents classified as caregivers were then asked to complete the remaining Caregiver Module questions, which include caregiver-reported information about the care recipient: gender, age, relationship, and major health condition. We categorized care recipient age as 0-17, 18-34, 35-64, 65-74, and 75 or older. We classified the relationship to the care recipient as parent or parent-in-law, spouse, other relative, and non-relative. There were 26 conditions listed on the BRFSS plus an “other” category, but we report only the most frequently reported diagnoses: Alzheimer’s disease or dementia, cancer, heart disease, diabetes, arthritis, and stroke.

Caregivers also reported the area in which the care recipient needs most help: self-care, household care, communicating with others, learning or remembering, seeing or hearing, moving around within the home, transportation outside the home, getting along with people, feeling anxious or depressed, or something else. Caregivers reported how long they had provided care for the care recipient, which we categorized as 0-12 months, 13-24 months, 25-60 months, and more than 60 months. Likewise, caregivers reported the number of hours in an average week they provide care to the care recipient; we classified this as 0-8 hours,

9-19 hours, 20-39 hours, and 40 hours or more to align with typical employment hours. Finally, caregivers were asked to identify the greatest difficulty they faced in caregiving: financial burden, not enough time for him/herself, not enough time for family, interferes with work, creates stress, creates or aggravates health problems, affects family relationships, another difficulty, or no difficulty. We created an indicator of whether caregivers reported any difficulty versus no difficulty.

Rural and Urban Residence

We classified respondents as living in a rural area if they lived outside of a Metropolitan Statistical Area (MSA), which is assigned based on respondents' residence. Specifically, people classified as living in an urban area lived in the center city of an MSA, outside the center city of an MSA but inside the county containing the center city, or inside a suburban county of the MSA.

Financial & Health Barriers

We defined a financial barrier as having an annual household income <\$25,000 or reporting they were not able to see a doctor when needed in the past year because of cost. We used this income level because it was close to the 2011 and 2012 federal poverty level (FPL) for a family of four (\$22,350¹⁹ and \$23,050,²⁰ respectively). The BRFSS collects income data in increments – e.g., \$20,000-24,999 – so it was not possible to use cutpoints that reflect the FPL exactly. We defined a health barrier as reporting fair or poor general health (versus excellent, very good, or good); having been diagnosed with at least two of the following six chronic health conditions: arthritis, cancer (excluding skin cancer), diabetes, cardiovascular disease (angina, myocardial infarction, or stroke), asthma, or chronic lung disease (emphysema or obstructive pulmonary disease), or having a disability (activities were limited because of a physical or mental health condition, or they used special equipment²¹). Although disability is conceptually distinct from health conditions or health status²², it is correlated with both²³ and we expected the impact of a chronic health condition or a disability on a caregiver's ability to provide care would be similar since either could require additional time to manage; therefore, we combined health and disability into a single type of potential barrier. In our sample, 58% of people with multiple chronic conditions also had a disability. When we compared caregivers with only a disability to those with only multiple chronic conditions we found only one difference: caregivers with only multiple chronic conditions were older than those with only a disability. Otherwise, the two groups had similar demographic characteristics (sex, race/ethnicity, education, rural residence) and there were no differences in their caregiving experiences (average hours of care provided, duration of caregiving, type of care provided, care recipient health condition, or caregiving-related difficulties).

We classified each respondent as having, or not having each of these barriers and also created a four-level indicator of barriers present: financial barrier only, health barrier only, both financial and health barriers, and neither financial nor health barrier.

Covariates

All data collected through the BRFSS are self-reported. We included respondents' gender, age group, highest level of educational attainment, employment status, race/ethnicity category, household income range, and marital status. If self-reported age was missing (0.3% of respondents), we used the imputed age variable available within the BRFSS dataset. For other variables, we created a "missing" category for covariates. We collapsed categories for age (from 5-year increments to five categories), education (from six to three categories), and household income (from eight to five categories) to assure we had an adequate number of respondents for regression analyses.

We created a variable to indicate whether respondents had any children under age 18 living in the household. We also created indicator variables for whether respondents had any health insurance coverage at the time of the interview, whether they reported they had at least one personal health care provider, and whether their last routine medical visit was within the past year. As described above, the BRFSS included questions about six chronic conditions. We used these variables together to indicate whether respondents had at least one chronic condition or multiple (≥ 2) chronic conditions.

Statistical Analysis

We included BRFSS respondents who were classified as caregivers, had a non-missing MSA code, could be classified as having or not having health and financial barriers, and reported whether they experienced any difficulties related to caregiving. Additionally, we limited our sample to respondents who had valid responses to age, sex, race/ethnicity, and education since we included these variables in the regression models. We allowed for missing information about caregiver experience.

We calculated the weighted proportion of caregivers overall and by rural residence. We also described the demographic and health status characteristics and the caregiving experiences of rural and urban caregivers and used chi-square tests to compare proportions across groups. Finally, we compared the demographic, health, and caregiving characteristics of rural and urban caregivers by their barrier category: financial barrier only, health barrier only, both financial and health barriers, and neither barrier. We used log-binomial regression models to estimate the adjusted prevalence ratios (PR) for having a financial barrier or a health barrier.²⁰ We also used a log-binomial regression model to assess the association between living in a rural area and reporting any difficulty associated with caregiving, after accounting for barriers and other demographic and household characteristics.

Data were weighted using the appropriate weight variable in the BRFSS public data file based on the survey version(s) on which the Caregiver Module appeared in each state. We also included primary sampling units and stratum weights in our weighting statements to appropriately calculate standard errors. All analyses were conducted using survey (svy) commands with subpopulation statements as appropriate (e.g., to restrict to respondents who were caregivers) in Stata version 13.1 (College Station, TX).

Results

Across the 10 states, the prevalence of caregiving was higher in rural areas (21.4%, 95% CI: 20.4-22.5) than in urban areas (19.0%, 95% CI: 18.0-19.9; $p=0.0005$). Rural caregivers had lower educational attainment and income than urban caregivers, were more likely to be married or partnered but less likely to have children under age 18 living in the household, and were more likely to be white, non-Hispanic (Table 1). In terms of health and health care access, rural caregivers were more likely to report having fair or poor health and have multiple chronic conditions than urban caregivers. Rural caregivers also were significantly more likely than urban caregivers to report they did not see a doctor when they needed to during the past year because of cost. Rural caregivers more frequently had financial barriers than urban caregivers (38.1% versus 31.0%, $p=0.0001$), but the prevalence of health barriers was similar (43.3% versus 40.6%, $p=0.18$).

The characteristics of care recipients and the caregivers' activities were similar for rural and urban caregivers (Table 2). Caregivers in rural areas were slightly more likely to provide care for a spouse (12.8% versus 10.3%, $p=0.03$). Caregivers in urban areas were more likely to report that caregiving created any difficulty (59.1% versus 52.1%, $p=0.0001$); specifically, urban caregivers were more likely to say caregiving did not leave them enough time for themselves (9.0% versus 5.8%, $p=0.002$) and caregiving affects their family relationships (5.0% versus 2.9%, $p=0.007$). The prevalence of other caregiving-related difficulties, including financial burden and creating or aggravating health problems, was similar across rural and urban respondents.

Among rural caregivers, 14.0% had only a financial barrier, 19.2% had only a health barrier, 24.0% had both barriers, and 42.7% had neither barrier. Among urban caregivers, 13.0% had only a financial barrier, 22.6% had only a health barrier, 17.9% had both barriers, and 46.4% had neither barrier. Caregivers with a financial barrier were more commonly women, especially in rural areas, than caregivers with no barriers (Table 3). In both rural and urban areas, caregivers with a financial barrier tended to be younger adults while caregivers with a health barrier were mostly middle-aged or older adults. Caregivers with only a financial barrier were least likely to have health care coverage, have a personal doctor, or have had a health check-up in the past year, while caregivers with only a health barrier had the highest levels of health insurance coverage, personal provider, and recent check-ups.

The experiences of caregivers varied based on whether they had any financial or health barriers, but differences tended to be consistent across rural or urban areas (Table 3). Specifically, caregivers with no barriers had been providing care for less time, on average, than caregivers with barriers and also tended to provide fewer hours of care in an average week. Caregiving related difficulties did differ by both the presence of barriers and rural residence. Stress was the most commonly-reported caregiving-related difficulty, regardless of barriers or rural residence. In both rural and urban areas, having a health barrier was associated with a higher prevalence of caregiving creating or aggravating health problems, and when the health barrier was present along with a financial barrier, this caregiving-related health difficulty was even more commonly reported. Caregivers with no barriers more

frequently reported that caregiving created difficulties related to their time or family relationships than caregivers with barriers.

After accounting for demographic differences, rural caregivers were significantly more likely than urban caregivers to have a financial barrier (Table 4). Women, middle-aged adults, and people who were not white, non-Hispanic were more likely to have a financial barrier. There was no difference in the presence of health barriers among rural compared to urban caregivers after accounting for demographic differences. Health barriers were associated with increasing age and with lower educational attainment, but not with rural residence.

Overall, 48% of rural caregivers and 41% of urban caregivers said caregiving created no difficulty ($p=0.0001$). After adjusting for the presence of financial and health barriers, demographic characteristics, and the duration and frequency of care, rural caregivers remained less likely to report a caregiving-related difficulty than their urban peers ($PR=0.90$, 95% CI: 0.84-0.95, $p<0.001$; Table 5). Having a financial or health barrier was not associated with reporting a difficulty. However, longer durations of caregiving and higher weekly caregiving frequency were associated with a significantly greater prevalence of reporting a difficulty.

Discussion

More than half of caregivers had a financial or health barrier, and caregivers living in rural areas were particularly likely to have financial barriers. These findings generally are in agreement with earlier population-based studies of US adults which have found greater financial challenges for rural caregivers compared to urban caregivers.^{14,25} This also reflects differences in the general population between rural and urban residents, with rural adults having lower income than urban adults.²⁶ Although there is evidence of a higher prevalence of chronic conditions and their risk factors among people living in rural areas,²⁷ we found rural and urban caregivers were equally likely to experience health barriers themselves.

In spite of the higher frequency of financial barriers, rural caregivers reported fewer caregiving-related difficulties than their urban peers. It is not clear from these data why rural caregivers experienced more burdens but did not perceive difficulty in the caregiving role. Previous research has found that caregivers in rural areas tend to have approach-based coping strategies,²⁸ meaning that they face potential stressors directly and use strategies like positive reframing, seeking social support, or problem solving to reduce the negative impact of stressors rather than avoiding them.²⁹⁻³¹ Approach-based coping has been associated with higher levels of caregiver resilience³² and lower levels of caregiver burden, anxiety, and perceived stress.³⁰⁻³⁷ Although previous studies have found that caregivers in urban areas also generally utilize approach-based coping,²⁸ it is possible that rural caregivers in our study were more likely to employ it and therefore perceived fewer difficulties related to caregiving than their urban peers. However, we did not have a measure of coping strategy so additional research is needed to test this hypothesis. People living in rural areas often are characterized by self-reliance¹⁴ and O'Connell et al. hypothesized that rural caregivers might be better able to identify informal and social supports than their urban peers since they

are faced with limited service options.²⁸ Together these characteristics could contribute to rural caregivers' perception that caregiving does not create difficulties even while they face financial or health limitations. This idea is supported somewhat by the data: urban caregivers were more likely than rural caregivers to report that the greatest difficulty they faced in caregiving was not having enough time for themselves or experiencing difficulties related to family relationships. More research is needed to investigate whether rural caregivers are more adept at seeking and engaging support from others and if this results in them perceiving fewer difficulties associated with providing care.

In the adjusted model, experiencing a financial and/or health barrier was not associated with reporting any caregiving-related difficulty for rural or urban caregivers, but the duration and frequency of care were associated with difficulties. Using BRFSS data, Kusano et al. previously found that caregivers who provided more hours of care per week (20-39 hours) were more likely to report that caregiving created a financial difficulty compared to caregivers who provided less care per week (0-8 hours).³⁸

Caregivers with their own chronic health conditions may be at risk of exacerbating them if they neglect their own care in order to tend to the needs of others.³⁹ Approximately one in six caregivers in this sample delayed a medical visit due to cost when they needed care, and rural caregivers were marginally more likely to report not seeing a doctor because of cost. Caregivers who had both financial and health barriers were most likely to report that caregiving created or aggravated their own health problems. Additional research is needed to understand whether these caregivers need additional supports to remain in the caregiving role and maintain their own health.

Women constitute the majority of caregivers – around 62% of caregivers in this study were women regardless of place of residence – but were particularly overrepresented in the group of caregivers classified as having both financial and health barriers. In the adjusted models, women caregivers were more likely to have financial barriers and to report caregiving-related difficulties. When developing programs to support caregivers, women in particular may benefit from financial support.

The strengths of this study include its population-based sample of community-dwelling adults and the use of questions that have been cognitively tested and previously used on the BRFSS. However, this study included respondents from only a subset of states and therefore may not reflect the experiences of caregivers across the US. We also used a coarse measure of rurality, the metropolitan status code, which does not allow for further divisions into highly rural or frontier areas, for example. Other rural measurement systems like the Rural Urban Commuting Areas include additional categories that would allow for more detailed comparisons; however, the public BRFSS data files do not include geographic indicators like county or zip code (to maintain anonymity) and therefore it was not possible to use an external classification system. Also, states vary in their sampling of BRFSS respondents and it is possible that people in highly rural areas are underrepresented. Other study limitations include the cross-sectional nature of the data, which means it is not possible to identify causal mechanisms. For example, it is not clear whether caregivers had financial barriers before they began providing care or if they resulted from the caregiving role. Distinguishing

the role of caregiving in creating barriers from the role of barriers in influencing the caregiving experience will require longitudinal data. Finally, there are differences between the definition of caregiving used on the BRFSS and those in other surveys and therefore this study likely included people who would not have been classified as caregivers in other studies because of a small number of hours per week, a limited range of activities with which they provided assistance, or the possibility that caregivers did not live with the care recipient.⁴⁰

Conclusion

Overall, we found a high prevalence of financial and health barriers among caregivers, and rural caregivers more frequently experienced financial barriers than urban caregivers. Nonetheless, nearly half of caregivers reported that providing care did not create any difficulties for them and rural caregivers were less likely to experience difficulties than their urban peers. Rural caregivers' coping strategies or skills in identifying informal supports may explain this difference, but additional research is needed to explore this hypothesis.

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References

1. Talley RC, Crews JE. Framing the public health of caregiving. *Am J Public Health*. 2007; 97(2): 224–228. DOI: 10.2105/AJPH.2004.059337 [PubMed: 17194871]
2. Wolff JL, Kasper JD. Caregivers of frail elders: updating a national profile. *The Gerontologist*. 2006; 46(3):344–356. [PubMed: 16731873]
3. 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.doi: 10.5888/pcd10.130090 [PubMed: 23948336]
4. Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Aff Proj Hope*. 1999; 18(2):182–188.
5. Aikens JE, Rosland A-M, Piette JD. Improvements in illness self-management and psychological distress associated with telemonitoring support for adults with diabetes. *Prim Care Diabetes*. 2015; 9(2):127–134. DOI: 10.1016/j.pcd.2014.06.003 [PubMed: 25065270]
6. DeFries EL, McGuire LC, Andresen EM, Brumback BA, Anderson LA. Caregivers of older adults with cognitive impairment. *Prev Chronic Dis*. 2009; 6(2):A46. [PubMed: 19288989]
7. Bucki B, Spitz E, Etienne A-M, Le Bihan E, Baumann M. Health capability of family caregivers: how different factors interrelate and their respective contributions using a Bayesian approach. *BMC Public Health*. 2016; 16(1):364.doi: 10.1186/s12889-016-3027-8 [PubMed: 27125282]
8. Davis LL, Chestnutt D, Molloy M, Deshefy-Longhi T, Shim B, Gilliss CL. Adapters, strugglers, and case managers: a typology of spouse caregivers. *Qual Health Res*. 2014; 24(11):1492–1500. DOI: 10.1177/1049732314548879 [PubMed: 25189535]

9. Dwyer JW, Miller MK. Determinants of primary caregiver stress and burden: area of residence and the caregiving networks of frail elders. *J Rural Health Off J Am Rural Health Assoc Natl Rural Health Care Assoc.* 1990; 6(2):161–184.
10. Bigbee JL, Musil C, Kenski D. The health of caregiving grandmothers: a rural-urban comparison. *J Rural Health Off J Am Rural Health Assoc Natl Rural Health Care Assoc.* 2011; 27(3):289–296. DOI: 10.1111/j.1748-0361.2010.00340.x
11. Kumar V, Acanfora M, Hennessy CH, Kalache A. Health status of the rural elderly. *J Rural Health Off J Am Rural Health Assoc Natl Rural Health Care Assoc.* 2001; 17(4):328–331.
12. Thorpe JM, Van Houtven CH, Sleath BL, Thorpe CT. Rural-urban differences in preventable hospitalizations among community-dwelling veterans with dementia. *J Rural Health Off J Am Rural Health Assoc Natl Rural Health Care Assoc.* 2010; 26(2):146–155. DOI: 10.1111/j.1748-0361.2010.00276.x
13. Danzl MM, Hunter EG, Campbell S, et al. “Living with a ball and chain”: the experience of stroke for individuals and their caregivers in rural Appalachian Kentucky. *J Rural Health Off J Am Rural Health Assoc Natl Rural Health Care Assoc.* 2013; 29(4):368–382. DOI: 10.1111/jrh.12023
14. Easter-Seals_NAC_Caregiving_in_Rural.pdf. http://www.caregiving.org/wp-content/uploads/2014/01/Easter-Seals_NAC_Caregiving_in_Rural.pdf. Accessed June 14, 2016
15. McGuire L, Bouldin EL, Andresen EM, Anderson LA. Examining modifiable health behaviors, body weight, and use of preventive health services among caregivers and non-caregivers aged 65 years and older in Hawaii, Kansas, and Washington using 2007 BRFSS. *J Nutr Health Aging.* 2010; 14(5):373–379. [PubMed: 20424805]
16. Horwitz ME, Rosenthal TC. The impact of informal care giving on labor force participation by rural farming and nonfarming families. *J Rural Health Off J Am Rural Health Assoc Natl Rural Health Care Assoc.* 1994; 10(4):266–272.
17. Mokdad AH. The Behavioral Risk Factors Surveillance System: past, present, and future. *Annu Rev Public Health.* 2009; 30:43–54. DOI: 10.1146/annurev.publhealth.031308.100226 [PubMed: 19705555]
18. Centers for Disease Control and Prevention (CDC). Characteristics and health of caregivers and care recipients—North Carolina, 2005. *MMWR Morb Mortal Wkly Rep.* 2007; 56(21):529–532. [PubMed: 17538528]
19. 2011 Poverty Guidelines, Federal Register Notice. ASPE; <https://aspe.hhs.gov/2011-poverty-guidelines-federal-register-notice>. Accessed June 15, 2017
20. 2012 HHS Poverty Guidelines | ASPE. <https://aspe.hhs.gov/2012-hhs-poverty-guidelines>. Accessed June 15, 2017
21. Centers for Disease Control and Prevention (CDC). State-specific prevalence of disability among adults—11 states and the District of Columbia, 1998. *MMWR Morb Mortal Wkly Rep.* 2000; 49(31):711–714. [PubMed: 10958586]
22. World Health Organization. Towards a Common Language for Functioning, Disability, and Health: The International Classification of Functioning, Disability, and Health. <http://www.who.int/classifications/icf/icfbeginnersguide.pdf>. Published 2002. Accessed August 28, 2016
23. Office of the Surgeon General (US), Office on Disability (US). The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities. Rockville (MD): Office of the Surgeon General (US); 2005. <http://www.ncbi.nlm.nih.gov/books/NBK44667/>. Accessed August 29, 2016
24. Barros AJD, Hirakata VN. Alternatives for logistic regression in cross-sectional studies: an empirical comparison of models that directly estimate the prevalence ratio. *BMC Med Res Methodol.* 2003; 3:21.doi: 10.1186/1471-2288-3-21 [PubMed: 14567763]
25. Ehrlich K, Boström A-M, Mazaheri M, Heikkilä K, Emami A. Family caregivers’ assessments of caring for a relative with dementia: a comparison of urban and rural areas. *Int J Older People Nurs.* 2015; 10(1):27–37. DOI: 10.1111/opn.12044 [PubMed: 24433340]
26. Holder, KA., Fields, A., Lofquist. Rurality Matters | Random Samplings. <http://blogs.census.gov/2016/12/08/rurality-matters/>. Accessed February 24, 2017

27. Bolin JN, Bellamy GR, Ferdinand AO, et al. Rural Healthy People 2020: New Decade, Same Challenges. *J Rural Health Off J Am Rural Health Assoc Natl Rural Health Care Assoc.* 2015; 31(3):326–333. DOI: 10.1111/jrh.12116
28. O’Connell ME, Germaine N, Burton R, Stewart N, Morgan DG. Degree of rurality is not related to dementia caregiver distress, burden, and coping in a predominantly rural sample. *J Appl Gerontol Off J South Gerontol Soc.* 2013; 32(8):1015–1029. DOI: 10.1177/0733464812450071
29. Suls J, Fletcher B. The relative efficacy of avoidant and nonavoidant coping strategies: a meta-analysis. *Health Psychol Off J Div Health Psychol Am Psychol Assoc.* 1985; 4(3):249–288.
30. Zucchella C, Bartolo M, Pasotti C, Chiapella L, Sinforiani E. Caregiver burden and coping in early-stage Alzheimer disease. *Alzheimer Dis Assoc Disord.* 2012; 26(1):55–60. DOI: 10.1097/WAD.0b013e31821aa6de [PubMed: 21537145]
31. Roche L, Croot K, MacCann C, Cramer B, Diehl-Schmid J. The Role of Coping Strategies in Psychological Outcomes for Frontotemporal Dementia Caregivers. *J Geriatr Psychiatry Neurol.* 2015; 28(3):218–228. DOI: 10.1177/0891988715588830 [PubMed: 26072312]
32. Wilks SE, Little KG, Gough HR, Spurlock WJ. Alzheimer’s aggression: influences on caregiver coping and resilience. *J Gerontol Soc Work.* 2011; 54(3):260–275. DOI: 10.1080/01634372.2010.544531 [PubMed: 21462058]
33. Goode KT, Haley WE, Roth DL, Ford GR. Predicting longitudinal changes in caregiver physical and mental health: a stress process model. *Health Psychol Off J Div Health Psychol Am Psychol Assoc.* 1998; 17(2):190–198.
34. Di Mattei VE, Prunas A, Novella L, Marcone A, Cappa SF, Sarno L. The burden of distress in caregivers of elderly demented patients and its relationship with coping strategies. *Neurol Sci Off J Ital Neurol Soc Ital Soc Clin Neurophysiol.* 2008; 29(6):383–389. DOI: 10.1007/s10072-008-1047-6
35. del-Pino-Casado R, Pérez-Cruz M, Frías-Osuna A. Coping, subjective burden and anxiety among family caregivers of older dependents. *J Clin Nurs.* 2014; 23(23-24):3335–3344. [PubMed: 25562084]
36. Gaugler JE, Eppinger A, King J, Sandberg T, Regine WF. Coping and its effects on cancer caregiving. *Support Care Cancer Off J Multinatl Assoc Support Care Cancer.* 2013; 21(2):385–395. DOI: 10.1007/s00520-012-1525-5
37. Silva N, Crespo C, Carona C, Canavarró MC. Mapping the caregiving process in paediatric asthma: Parental burden, acceptance and denial coping strategies and quality of life. *Psychol Health.* 2015; 30(8):949–968. DOI: 10.1080/08870446.2015.1007981 [PubMed: 25601492]
38. Kusano CT, Bouldin ED, Anderson LA, et al. Adult informal caregivers reporting financial burden in Hawaii, Kansas, and Washington: Results from the 2007 Behavioral Risk Factor Surveillance System. *Disabil Health J.* 2011; 4(4):229–237. DOI: 10.1016/j.dhjo.2011.08.001 [PubMed: 22014670]
39. Reinhard, SC., Given, B., Petlick, NH., Bemis, A. Supporting Family Caregivers in Providing Care. In: Hughes, RG., editor. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses.* Rockville (MD): Agency for Healthcare Research and Quality (US); 2008. *Advances in Patient Safety* <http://www.ncbi.nlm.nih.gov/books/NBK2665/>. Accessed July 27, 2016
40. Giovannetti ER, Wolff JL. Cross-survey differences in national estimates of numbers of caregivers of disabled older adults. *Milbank Q.* 2010; 88(3):310–349. DOI: 10.1111/j.1468-0009.2010.00602.x [PubMed: 20860574]

Table 1

Demographic and health characteristics of rural and urban caregivers.

Variable	Category	Rural Caregivers N=3,168	Urban Caregivers N=4,268	P-value [†]
		Weighted %	Weighted %	
Gender	Female	62.6	62.0	0.77
Age group	18–34	16.2	16.8	0.07
	35–44	12.8	15.7	
	45–54	23.4	24.4	
	55–64	25.5	24.5	
	65+	22.2	18.6	
Highest level of education	<High school	39.1	27.7	<0.0001
	High school or equivalent	35.2	31.2	
	Some college or higher	25.7	41.1	
Employment status	Employed, student, or homemaker	65.8	65.8	0.97
	Retired	19.8	19.2	0.64
	Unemployed or unable to work	14.5	15.0	0.70
Marital status	Married/Coupled	68.3	60.1	<0.0001
	Missing	0.1	0.2	
Children in household	At least one child <age 18	26.5	33.5	0.007
	Missing	0	0.8	
Household Income	Less than \$15,000	9.9	7.4	<0.0001
	\$15,000-\$24,999	20.7	16.8	
	\$25,000-\$34,999	32.7	26.8	
	\$35,000-\$49,999	17.8	16.3	
	\$50,000 or more	18.9	32.7	
Race/ethnicity	White, non-Hispanic	89.0	75.2	<0.0001
	Black, non-Hispanic	6.0	14.3	<0.0001
	Other or multiple race, non-Hispanic	2.8	4.4	0.04
	Any race, Hispanic	2.2	6.2	0.0006
Disability status	Has a limitation	28.0	27.2	0.67
General health	Fair or poor	22.7	18.1	0.004
Chronic health conditions ²	At least one	54.9	53.3	0.51
	Multiple (2)	23.9	20.4	0.02
Health insurance	Any coverage	84.9	86.4	0.50
	Missing	0.3	0.6	
Personal doctor	One or more	88.7	88.7	0.99
	Missing	0.1	0.1	
Medical costs	Did not see a doctor because of cost	17.6	14.6	0.04
Last routine medical check-up	Within the past year	70.7	74.0	0.14

Variable	Category	Rural Caregivers N=3,168	Urban Caregivers N=4,268	P-value ¹
		Weighted %	Weighted %	
	Missing	0.5	0.7	
Financial barrier ³	Present	38.1	31.0	0.0001
Health barrier ⁴	Present	43.3	40.6	0.18

¹ P-value based on chi-square test comparing weighted percentage of rural caregivers to urban caregivers in each category

² Chronic health conditions assessed: arthritis, asthma, non-skin cancer, cardiovascular disease, diabetes, and chronic lung disease

³ Financial barrier defined as having an annual household income <\$25,000 or not being able see a doctor when they needed to in the past year because of cost

⁴ Health barrier defined as having been diagnosed with multiple (≥ 2) chronic health conditions, having a disability, or having fair or poor self-rated general health

Table 2

Care recipient characteristics and caregiving details for rural and urban caregivers.

Variable	Category	Rural Caregivers N=3,168	Urban Caregivers N=4,268	p-value ¹
		Weighted %	Weighted %	
Care recipient gender	Female	62.7	63.3	0.74
Care recipient age	0–17	3.6	4.0	0.96
	18–34	4.8	4.8	
	35–54	12.5	13.5	
	55–64	13.2	13.5	
	65–74	17.3	16.4	
	75 or older	48.6	47.7	
Care recipient is caregiver's...	Parent or parent-in-law	41.6	43.6	0.38
	Spouse	12.8	10.3	0.03
	Other relative	30.2	31.3	0.59
	Non-relative	15.3	14.8	0.75
Care recipient's major health problem, identified by caregiver	Alzheimer's disease or dementia	12.3	12.0	0.82
	Cancer	10.1	8.9	0.35
	Diabetes	8.1	6.5	0.11
	Heart disease	7.2	6.0	0.26
	Arthritis	6.9	5.4	0.17
	Stroke	5.0	5.2	0.87
Area in which care recipient needs most help	Self-care	18.1	18.0	0.94
	Household care	29.3	29.9	0.74
	Communicating with others	1.9	2.2	0.47
	Learning or remembering	2.7	2.4	0.73
	Seeing or hearing	1.1	1.1	0.92
	Moving around within home	4.7	4.5	0.78
	Transportation outside the home	24.0	25.5	0.37
	Getting along with people	0.8	1.0	0.34
	Feeling anxious or depressed	4.7	4.3	0.68
	Something else	5.5	7.3	0.10
Length of care	0–3 months	20.2	23.1	0.24
	4–12 months	20.6	19.4	
	13–24 months	13.7	13.7	
	25–60 months	22.1	18.6	
	>60 months	23.4	25.1	
Hours of care provided per week, on average	0–8	53.5	57.3	0.13
	9–19	18.5	14.8	
	20–39	12.0	12.8	

Variable	Category	Rural Caregivers N=3,168	Urban Caregivers N=4,268	p-value ¹
		Weighted %	Weighted %	
	40 or more	16.0	15.1	
Greatest difficulty faced by caregiver	Financial burden	6.1	5.2	0.29
	Not enough time for him/herself	5.8	9.0	0.002
	Not enough time for family	5.6	4.7	0.23
	Interferes with work	3.2	3.5	0.60
	Creates stress	19.9	21.7	0.26
	Creates or aggravates health problems	3.0	2.8	0.74
	Affects family relationships	2.9	5.0	0.007
	Another difficulty	5.5	7.3	0.10
	No difficulty	47.9	40.9	0.0001

¹ P-value based on chi-square test comparing weighted percentage of rural caregivers to urban caregivers in each category

Table 3 Caregiver demographic, health care access, and caregiving experiences among caregivers with potential financial¹ or health² barriers and without these barriers, by rural and urban residence.

Characteristic	Rural Caregivers with...				Urban Caregivers with...			
	Financial Barrier/Only (n=484)	Health Barrier ² Only (n=659)	Both Barriers (n=791)	Neither Barrier (n=1,234)	Financial Barrier/Only (n=479)	Health Barrier ² Only (n=1,111)	Both Barriers (n=876)	Neither Barrier (n=1,802)
	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %
Gender	70.1	54.7	65.9	61.8	63.5	58.0	66.7	61.8
Age group								
18-34	24.8	5.2	16.9	17.9	32.3	9.4	12.7	17.1
35-44	15.5	5.3	13.5	14.9	17.3	8.4	17.0	18.4
45-54	20.8	22.4	21.2	25.9	15.6	20.6	27.3	27.6
55-64	22.2	34.3	22.4	24.3	16.9	31.4	21.6	24.4
65+	16.7	32.8	26.0	17.0	15.9	30.3	21.3	12.5
Race/ethnicity	81.5	94.2	82.3	92.9	78.6	83.6	66.1	60.9
White, non-Hispanic	81.5	94.2	82.3	92.9	78.6	83.6	66.1	60.9
Any coverage	63.3	95.8	77.4	91.3	61.4	95.5	75.3	93.3
Missing	0.8	0.05	0	0.5	0	0.4	0	1.0
One or more	78.5	95.1	87.2	90.0	69.6	96.1	88.1	90.8
Missing	0.05	0.6	0	0.02	0.02	0.2	0.2	0.1
Last routine medical check-up	55.8	84.6	66.6	71.6	52.8	83.4	72.7	75.8
Within the past year	55.8	84.6	66.6	71.6	52.8	83.4	72.7	75.8
Missing	1.3	0.7	0.6	0.2	0.3	1.0	0.3	0.8
Care recipient's major health problem (selected)	11.6	11.9	8.1	12.8	6.4	10.6	9.6	13.1
Alzheimer's disease or dementia	11.6	11.9	8.1	12.8	6.4	10.6	9.6	13.1
Cancer	10.0	9.0	7.5	10.3	10.2	8.2	8.8	7.4
Diabetes	4.8	5.4	6.6	7.9	9.2	4.5	5.8	4.9
Heart disease	6.0	8.6	6.6	7.9	7.2	5.2	7.2	5.6
Missing	16.8	12.0	13.1	11.8	10.0	8.1	10.1	9.5
Length of care	34.7	27.9	38.9	36.6	41.3	31.4	41.1	41.3
0-12 months	34.7	27.9	38.9	36.6	41.3	31.4	41.1	41.3
13-24 months	9.6	12.6	10.5	12.1	12.6	15.9	13.5	10.9
25-60 months	18.5	22.9	19.4	17.2	19.3	17.6	17.0	16.8
> 5 years	24.9	23.7	20.2	15.1	19.0	24.5	29.6	19.2

Characteristic	Rural Caregivers with...						Urban Caregivers with...									
	Financial Barrier ¹ Only (n=484)		Health Barrier ² Only (n=659)		Both Barriers (n=791)		Neither Barrier (n=1,234)		Financial Barrier ¹ Only (n=479)		Health Barrier ² Only (n=1,111)		Both Barriers (n=876)		Neither Barrier (n=1,802)	
	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %	Weighted %
	Missing	12.1	12.9	13.1	19.0	7.8	10.5	8.8	11.8							
Average hours of care per week	0-8	39.6	50.5	35.2	59.6	48.9	55.0	31.0	56.5							
	9-19	13.9	17.5	18.8	16.0	9.4	13.8	18.8	15.5							
	20-39	12.7	9.5	15.5	7.9	14.2	9.1	13.9	11.8							
	40 or more	23.1	13.8	20.4	8.1	13.6	12.3	21.8	8.9							
	Missing	10.8	8.8	10.0	8.4	13.9	9.7	14.5	7.2							
Greatest difficulty faced by caregiver	Financial burden	7.2	5.9	7.9	4.7	4.1	3.3	12.0	3.8							
	Not enough time for him/herself	6.9	5.2	3.9	6.8	10.1	8.4	9.4	8.9							
	Not enough time for family	4.7	6.0	3.1	7.2	3.9	3.3	4.0	5.8							
	Interferes with work	3.1	3.4	2.2	3.6	3.9	3.9	2.5	3.7							
	Creates stress	19.0	21.6	23.9	17.3	15.6	21.5	20.9	23.8							
	Creates or aggravates health problems	1.3	3.5	8.8	0.1	0.3	4.4	8.0	0.7							
	Affects family relationships	1.9	1.9	3.0	3.6	6.2	7.3	2.6	4.3							
	Another difficulty	4.6	5.3	6.9	5.2	10.0	6.7	6.4	7.1							
	No difficulty	51.3	47.1	40.2	51.6	45.9	41.1	34.2	41.9							

¹ Financial barrier defined as having an annual household income <\$25,000 or not being able to see a doctor when they needed to in the past year because of cost

² Health barrier defined as having been diagnosed with multiple (2) chronic health conditions, having a disability, or having fair or poor self-rated general health

Table 4 Regression models comparing the presence of financial and health barriers among rural and urban caregivers.

Characteristic	Financial Barrier		Health or Disability Barrier	
	PR (95%CI)	P-value	PR (95%CI)	P-value
Rural residence	Rural caregivers	1.33 (1.20–1.48)	1.00 (0.92–1.09)	0.99
	Urban caregivers	Ref	Ref	–
Gender	Female	1.16 (1.01–1.34)	0.96 (0.88–1.04)	0.33
	Male	Ref	Ref	–
Age group	18–34	Ref	Ref	–
	35–44	0.88 (0.70–1.11)	1.17 (0.90–1.53)	0.24
	45–54	0.80 (0.66–0.98)	1.49 (1.17–1.90)	0.001
	55–64	0.73 (0.60–0.90)	1.73 (1.37–2.19)	<0.001
	65+	0.91 (0.75–1.10)	2.11 (1.68–2.66)	<0.001
	White, non-Hispanic	0.61 (0.56–0.71)	0.88 (0.77–1.01)	0.08
Race and ethnicity category	Other than white, non-Hispanic	Ref	Ref	–
	<High school	Not included		
	High school or equivalent	Not included		
	Some college or higher	Not included		

PR: Prevalence ratio

Ref: Reference category in regression model (PR=1.0)

Not included: variable not included in model

Table 5

Regression model comparing caregivers experiencing any caregiving-related difficulty by rural and urban residence and presence of financial and/or health barriers.

Characteristic		Any Caregiving-Related Difficulty	
		PR (95%CI)	P-value
Rural residence	Rural caregivers	0.90 (0.84–0.95)	<0.001
	Urban caregivers	Ref	–
Barrier category	Financial only	0.95 (0.83–1.09)	0.46
	Health only	1.06 (0.98–1.15)	0.14
	Both financial and health	1.09 (0.95–1.11)	0.06
	Neither financial nor health	Ref	–
Gender	Female	1.09 (1.00–1.17)	0.04
	Male	Ref	–
Age group	18–34	Ref	–
	35–44	1.14 (0.97–1.33)	0.11
	45–54	1.16 (0.99–1.35)	0.06
	55–64	1.14 (0.98–1.34)	0.10
	65+	0.99 (0.85–1.17)	0.94
Race and ethnicity category	White, non-Hispanic	1.08 (0.97–1.20)	0.16
	Other than white, non-Hispanic	Ref	–
Children in the household	Any	1.03 (0.94–1.12)	0.58
	None	Ref	–
Length of care	0–12 months	Ref	–
	>12 months	1.15 (1.06–1.23)	<0.001
	Missing	0.97 (0.85–1.11)	0.66
Average hours of care per week	0–8	Ref	–
	>8	1.33 (1.23–1.44)	<0.001
	Missing	0.93 (0.80–1.08)	0.35

PR: Prevalence ratio

Ref: Reference category in regression model (PR=1.0)