



## ORIGINAL RESEARCH

# Geographic differences in the unpaid caregiver experience from the National Study of Caregiving (NSOC)

### AUTHORS

Mara W Rosenberg<sup>1</sup> MD, MCR, Internal Medicine Resident \*

Elizabeth Eckstrom<sup>2</sup> MD, MPH, Professor of Medicine

### CORRESPONDENCE

\*Ms Mara W Rosenberg [rosenberg.mara@gmail.com](mailto:rosenberg.mara@gmail.com)

### AFFILIATIONS

<sup>1</sup> Division of Internal Medicine, Legacy Emanuel and Good Samaritan Hospitals, 1015 NW 22nd Ave, Portland, OR 97210, USA

<sup>2</sup> Division of General Internal Medicine & Geriatrics, Oregon Health & Science University, 3181 SW Sam Jackson Park Rd, Portland, OR 97239, USA

### PUBLISHED

14 October 2020 Volume 20 Issue 4

### HISTORY

RECEIVED: 28 April 2020

REVISED: 23 August 2020

ACCEPTED: 25 August 2020

### CITATION

Rosenberg MW, Eckstrom E. Geographic differences in the unpaid caregiver experience from the National Study of Caregiving (NSOC). *Rural and Remote Health* 2020; 20: 6062. <https://doi.org/10.22605/RRH6062>

This work is licensed under a [Creative Commons Attribution 4.0 International Licence](https://creativecommons.org/licenses/by/4.0/)

## ABSTRACT:

**Introduction:** The objective of this cross-sectional, descriptive study was to identify unpaid caregiver differences in demographics, competing work responsibilities, support, health, caregiver burden, and interaction with healthcare professionals in US metropolitan and non-metropolitan settings.

**Methods:** This study leveraged the nationally representative survey of older adults and their unpaid caregivers residing in the USA: the 2017 National Health and Aging Trends Study and National Study of Caregiving. Participants were unpaid caregivers for community-dwelling older adults.

**Results:** A total of 2278 unique unpaid caregivers corresponding to 1431 care recipients were investigated for this study. Non-metropolitan caregivers had significantly lower income than their

metropolitan counterparts, were more likely to be married or have a partner, missed less work, and, when traveling to provide care, traveled on average fewer minutes than metropolitan caregivers. However, there were no significant differences in relationship to caregiver, impact on primary work responsibilities, financial assistance, resource utilization or access, caregiver burden, relationship with primary care providers, or self-rated caregiver health.

**Conclusion:** Non-metropolitan caregivers experience lower income with possible greater familial support, but despite the financial disparities do not have higher caregiver burden, poorer self-rated health, or differences in other important measures. Additional studies that further divide the non-metropolitan cohort

into more refined categories by population and with larger sample sizes are essential for designing policy and programs to learn from

**Keywords:**

caregiver, caregiver burden, caregiver resilience, older adult, USA.

## FULL ARTICLE:

### Introduction

The older adult US population is expected to nearly double in the next 30 years, from 43.1 million to an estimated 83.7 million by 2050<sup>1</sup>. As the older adult population increases and modern medical treatments improve, there is also a skew of older adults towards the 'oldest old'<sup>2</sup>. With these population changes, more individuals will require physical or cognitive support.

Currently, 17.7 million individuals in the USA provide care to family members aged 65 years or older<sup>2,3</sup>. The economic value of services that unpaid caregivers provide to older adults is around \$375 billion yearly, double what is spent on homecare or nursing home services<sup>4</sup>. Although the aging process itself does not guarantee the need for assistance in daily activities, co-morbidities and disease processes of older adults make it much more likely. For example, 58.5% of older persons aged 85–89 years receive family caregiver help due to health or functional limitations while 76% of adults aged over 90 years require assistance<sup>5</sup>. The demand for caregivers will likely increase with the increase in the oldest old population<sup>2,5</sup>.

Further, the caregiver experience differs by geographic location. Studies have demonstrated that rural caregivers have more financial barriers than their urban counterparts (38.1% v 31%) and worse self-reported health status. However, they are less likely to report depression, caregiving burden, or difficulty in care<sup>6–9</sup>. These are important differences to investigate because rural regions have a disproportionate representation of older adults. In the rural USA, 17.5% of residents are 65 years or older compared to only 13.9% in urban areas. Rural counties make up 85% of the 1104 older-age counties<sup>10</sup>.

The present study leverages the National Study of Caregiving (NSOC) and the associated linked National Health and Aging Trends Study (NHATS) to provide the largest national study to date to examine differences between rural and urban residing caregivers. The dataset includes both longitudinal data as well as data focused on specific moments in time. The most recent time point was chosen as the focus of the analyses and therefore a cross-sectional descriptive analysis was used for this study. Variables were chosen based on previously identified factors that differed between rural and urban caregivers as well as variables proposed to influence caregiver burden<sup>6–9,11</sup>. Such variables included demographics, competing work responsibilities, support, health, caregiver burden, and interaction with healthcare professionals<sup>12,13</sup>.

### Methods

#### Data

This study leveraged publicly available data from the 2017

rural caregivers and build resilience among all care providers.

National Study of Caregiving Study Round III and the associated National Health and Aging Trends Study Round 8, a survey based dataset collected in 2017. A linked Metro-Nonmetro Indicator file was used for this analysis to characterize rural versus urban residence. NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and was conducted by the Johns Hopkins University<sup>12,13</sup>.

The NHATS study includes a comprehensive interview of Medicare enrollees aged 65 years or more, living in the contiguous USA. The NSOC study includes telephone interviews conducted on family or unpaid helpers to participants from the NHATS who required assistance with self-care, mobility, or household activities. The two datasets are linked by a unique care recipient numerical ID. Caregivers were initially identified from NHATS Round 1 (2011) with a 68.1% unweighted response rate. At a 6-year follow-up (NSOC Round 3, 2017), 2652 caregivers were interviewed, corresponding with 1697 care recipients. Of these, 2278 care recipients had annotations for residential location. Therefore, 2278 caregivers, corresponding with 1431 care recipients, were used for this study and were connected across the datasets with a unique care recipient identification number. The 2017 survey data were chosen for a cross-sectional analysis in this study. Weights to adjust for caregiver non-response and sampling selection were already calculated and provided within the NSOC dataset<sup>12</sup>. All analyses were performed with these weighted values.

### Variables

Caregivers were characterized based on the care recipient's geographic location: metropolitan or non-metropolitan. Metropolitan residence included counties in metropolitan areas of fewer than 250 000, counties in metropolitan areas of 250 000 – 1 million in population, and those over 1 million in size. These categories corresponded with the 2013 Rural–Urban Continuum Codes (RUCC) of 1–3<sup>14</sup>. Non-metropolitan caregivers included non-metropolitan rural areas with a population of up to 19 999 individuals either adjacent or not adjacent to a metropolitan area, urban population of 2500 to 19 999 either adjacent or not adjacent to a metropolitan area, and non-metropolitan urban populations of 20 000 or more adjacent or not to a metropolitan area. These had corresponding RUCC codes of 4–9<sup>12,13</sup>.

Caregiver characteristics and responsibilities identified from the NSOC data included demographics, information on primary job responsibilities, caregiver assistance and resources, caregiver burden, distance to recipient home, health, and interaction with healthcare providers. Care recipient characteristics included functional status and whether the person was housebound.

Caregiver demographics included age (year of NSOC study subtracted from date of birth listed), gender, race, education, household size, partner in household, and income. Relationship to care recipient was classified as spouse, child (daughter, son, daughter-in-law, or son-in-law), parent, other relative (sister, brother, sister-in-law, brother-in-law, grandchild, niece/nephew, uncle/aunt, cousin, stepchild, or step grandchild), or non-relative. Caregiver's current work status included whether they had a paying job, missed work for caregiving, caregiving affected their work, they carried more than one job, and whether the unpaid caregiver also had paid in-home care.

Caregiving resources were evaluated based on whether they looked for assistance, received training, or attended a caregiving support group. Caregiver burden was evaluated through binary self-reported difficulty with finances, emotional difficulty, or physical difficulty with caregiving. Caregiver depression was determined via Patient Health Questionnaire 2 (PHQ-2) (score of  $\geq 3$  scored positive for depression). Similarly anxiety was evaluated using General Anxiety Disorder Anxiety Test Questionnaire 2 (GAD-2) (score of  $\geq 3$  scored positive for anxiety)<sup>15</sup>. These scoring methods are widely used and have established validity and reliability. A GAD-2 cut-off score of 3 or more has been demonstrated to have a sensitivity of 0.76 and specificity of 0.81 for anxiety, while a PHQ-2 cut-off score of 3 or more has a sensitivity and specificity of 0.83 and 0.92 respectively for major depression<sup>16,17</sup>.

Caregivers were asked to evaluate the effect of caregiving on valued activities including visiting family or friends, attending religious service, participating in group activity, going out for enjoyment, working, volunteering, and providing care. If at least one of these variables was positive, then caregiving was reported to have had an impact on desired activities.

Care recipient characteristics were derived from the NHATS dataset. Functional status was evaluated via Riffin et al 2019, which used a composite of disability with dementia to determine overall function<sup>11</sup>. Dementia status was predefined within the NHATS dataset based on report by the sample person or proxy that a doctor had diagnosed him/her with dementia or Alzheimer's; a score indicating probable dementia on the AD8 Dementia Screening Interview; or in scoring on cognitive tests that evaluated for memory, orientation, and executive function<sup>18</sup>. Disability was determined if the care recipient required assistance with three or more basic activities of daily living including bathing, eating, dressing, toileting, transferring, and indoor mobility. A summary of these investigated variables is included in Supplementary table 1.

### **Supplementary table 1: Summary of investigated variables**

#### **Statistical analysis**

Given the binary RUCC geographic classification of the data, bivariate analyses were performed on all listed variables to detect statistical significance between each feature and site of residence, with alpha equal to 0.05. Categorical variables were tested with a  $\chi^2$  test of independence and Welch's *t*-test was used for continuous variables due to unequal population sizes. Benjamini-

Hochberg correction was used to adjust the *p*-values for multiple hypothesis testing. Multivariable regression was performed on the related significant features from the bivariate analysis ( $p < 0.05$ ) in addition to age and sex in combination with rural status to assess for combined impact on caregiver burden (defined as financial, emotional, or physical burden) and caregiver health status. All analyses used weighted values as defined within the original NCOS survey to account for non-survey response and sampling bias. Within each variable, the caregivers without a response were excluded. Analyses were performed using R v.3.6.1 (R Foundation; <https://www.r-project.org>) and the 'survey' R package v4.0 (R Foundation; <http://r-survey.r-forge.r-project.org/survey>).

#### **Ethics approval**

The NHATS and NSOC data are publicly available data and do not contain identifiable personal health information. This study was deemed exempt from institutional review by Oregon Health & Science University Institutional Review Board.

#### **Results**

From 2278 caregivers, 1849 cared for older adults in metropolitan regions while 429 cared for those in non-metropolitan areas. These corresponded to weighted *N* values of 17 191 181 and 3 718 904 respectively. Caregiver age and gender were not statistically different between geographic locations. The mean age was 57.3 years in metropolitan and 54.5 years in non-metropolitan regions, and across residences caregivers were predominantly female (64.4% in metropolitan regions and 63.6% in non-metropolitan) (Table 1). The relationship of caregivers to their care recipients showed no statistically significant difference between geographic regions, with 52.5% (9 030 948/17 191 181) and 44.9% (1 671 476/3 718 904) of caregivers being a child (or stepchild) of the care recipient in urban versus rural settings respectively ( $p > 0.05$ ). There were no statistically significant differences in race, education, household size, whether the caregiver had a paying job, had more than one job, and in self-rated health, depressive and anxiety symptoms.

Mean income and whether there was a partner in the household were significantly different between geographic sites ( $p < 0.05$ ). Mean income was significantly greater in metropolitan regions, at \$69,881 (standard error \$3545) compared to \$53,464 (standard error \$2887). Further, only 53.2% were partnered in metropolitan regions compared with 63.1% in non-metropolitan regions ( $p < 0.05$ ) (Table 1).

There were no significant differences in caregiving responsibilities between metropolitan and non-metropolitan caregivers. These included hours per week spent caregiving, number of caregivers, and other family involvement. Non-metropolitan caregivers did miss less work than metropolitan caregivers (16.3% v 35.0% respectively) and had a significantly shorter travel time to provide care (12.8% at 11–30 minutes v 21.1%) (Table 2).

There were no differences in self-rated caregiver burden financially, emotionally, or physically. No significant differences were observed in having time for self, exhaustion, the feeling of

caregiving being more than he/she could handle, or effect on valued activities (Table 2).

There were no significant metropolitan–non-metropolitan differences in the availability or utilization of caregiving resources. A total of 3.3% of metropolitan caregivers attended caregiving support groups compared with 3.2% of non-metropolitan caregivers ( $p=0.99$ ). The distribution of locations where caregivers sought assistance between government, providers, religious centers, or employers was even between geographic locations. Metropolitan caregivers did additionally seek out resources on their own beyond those previously listed (79.8% v 37.9%,  $p<0.05$ ) (Table 3).

Caregivers’ geographic location did not impact their relationships with medical providers. The majority of caregivers felt that doctors

always listened to them irrespective of location (67.6% and 75.6% in metropolitan and non-metropolitan respectively,  $p=0.37$ ). More than half of caregivers claimed that they always understood the care recipient’s health treatment (53.8% and 55.9% in metropolitan and non-metropolitan areas, respectively) (Table 3).

Significant features that differed between rural and urban settings in addition to age and sex were included in a multivariable regression model to account for their impact on overall caregiver burden and caregiver health. These variables included caregiver income, whether the caregiver was partnered, and distance to care recipient’s home. There remained no significant impact of geographic residence on caregiver burden (financial, emotional, or physical burden) (odds ratio 0.81–1.04). Further, there was no significant association between geographic location and caregiver health status (odds ratio 0.89–1.05) (Table 4).

**Table 1: Caregiver demographics**

Characteristic	Metro	Non-metro	Adjusted p-value
Total, weighted N	17 191 181 (1849)	3 718 904 (429)	
Mean age (IQR) (years)	57.3 (50–67)	54.5 (49–64)	0.34
Gender (%)			0.93
Male	35.6	36.4	
Female	64.4	63.6	
Race			0.34
White, non-Hispanic	70.4	81.9	
Black, non-Hispanic	13.6	9.6	
Hispanic	9.3	2.7	
Other	6.8	5.8	
Education (%)			0.17
<High school	6.5	4.6	
High school or GED	48.9	61.8	
> High school	44.6	33.5	
Relationship to care recipient (%)			0.37
Spouse	19.7	25.6	
Child	52.5	44.9	
Other relative	15.9	18.5	
Non-relative	11.9	10.9	
Caregiver has partner in household (%)	53.2	63.1	< 0.05
Household size, mean (SE)	1.68 (0.05)	1.54 (0.12)	0.58
Income last year, mean (SE)	69 881 (3545)	53 464 (2887)	< 0.05
Have paying job	41.3	51.7	0.95
Have more than one job (%)	16.3	15.6	0.95
Self-rated health (poor or fair) (%)	17.2	19.7	0.78
Depressive symptoms (PHQ-2 $\geq 3$ ) (%)	10.4	12.2	0.72
Anxiety symptoms (GAD-2 $\geq 3$ ) (%)	10.9	12.7	0.68

GED, General Education Diploma. IQR, interquartile range. SE, standard error.

**Table 2: Caregiving responsibilities and burden**

Responsibility/burden	Metro	Non-metro	Adjusted p-value
Mean hours per week spent caregiving (SE)	22.8 (1.4)	26.2 (2.6)	0.58
Help on regular schedule (%)	26.9	22.6	0.22
Caregiving affects primary work (%)	12.7	8.2	0.22
Have to miss work for caregiving (%)	35.0	16.3	<0.05
Mean hours of work missed per week (SE)	11.6 (1.5)	65.3 (28.1)	0.23
More than one caregiver involved (%)	37.5	37.6	0.99
Care recipient also has paid in-home care	4.2	3.8	0.92
Family members fairly share responsibility (%)	64.8	62.8	0.79
Travel time to recipient home (min) (%)			<0.05
0 (co-reside)	50.0	51.0	
≤10	24.1	33.4	
11–30	21.1	12.8	
≥31	4.8	2.7	
Caregiver burden (%)			
Financial	14.4	13.8	0.92
Emotional	37.1	40.0	0.69
Physical	16.1	21.4	0.08
Personal consequences of care			
Have no time for self (%)	13.5	11.5	0.78
Exhaustion (%)	15.4	16.4	0.89
Care more than can handle (%)	11.9	10.4	0.79
Caregiving effects on ≥1 valued activities (%)	18.5	21.8	0.79
Function of care recipient (%)			0.19
No dementia or severe disability	54.5	45.1	
Dementia but not severe disability	6.5	9.5	
No dementia but severe disability	16.9	25.0	
Both dementia and severe disability	11.4	7.1	
Care recipient homebound (%)	7.8	6.6	0.79

SE, standard error.

**Table 3: Caregiving resources**

Resource	Metro	Non-metro	Adjusted p-value
Attended caregiving support group (%)	3.3	3.2	0.99
Received training for caregiving (%)	7.0	10.7	0.22
Caregiver trained post hospitalization (%)	56.2	62.3	0.69
Sought additional assistance (%)	7.7	5.1	0.37
Found financial assistance (%)	10.5	9.8	0.89
Where looked for assistance (%)			
Government	65.3	85.0	0.08
Provider	50.9	55.0	0.89
Religious center	9.9	10.0	0.99
Employer	7.5	1.2	0.22
Own	79.8	37.9	< 0.05
How often talk to other medical providers (%)			0.81
Often	24.1	22.6	
Sometimes	45.0	49.6	
Rarely	30.9	27.9	
Doctors listen to caregivers (%)			0.37
Always	67.6	75.6	
Usually	20.7	13.0	
Sometimes	9.6	10.5	
Never	2.0	1.0	
Caregiver understands health treatment (%)			0.93
Always	53.8	55.9	
Usually	18.6	15.7	
Sometimes	14.8	14.1	
Never	12.8	14.4	



**Table 4: Multivariable regression analysis for caregiver burden and health status<sup>†</sup>**

Variable	Caregiver burden (OR, 95%CI)	Caregiver health status (OR, 95%CI)
Rural	0.92 (0.81–1.03)	0.96 (0.89–1.05)
Caregiver female	0.93 (0.81–1.07)	0.96 (0.86–1.07)
Caregiver age	1.00 (0.99–1.00)	1.00 (0.99–1.00)
Income (<\$30,000/year)	1.01 (0.87–1.18)	0.99 (0.91–1.1)
Caregiver has partner in household	0.93 (0.81–1.06)	0.96 (0.89–1.04)
Distance to recipient home (>10 min)	1.00 (0.88–1.15)	1.06 (0.98–1.15)

Numerical data displayed as the odds ratio (OR) with 95% confidence interval (CI).

This study leveraged a national survey of family and other unpaid caregivers of older adults and found that non-metropolitan caregivers had a lower income, traveled less time to care for their care-recipients, missed less work, and were more likely to have a partner at home than their metropolitan counterparts. Surprisingly, many other factors were similar across caregivers, irrespective of residence. There were no significant differences in relationship to caregiver, financial assistance, resource utilization or access, caregiver burden, relationship with primary care providers, or self-rated caregiver health. Further, in a multivariable regression analysis accounting for the differences between urban and rural settings, rural status remained non-significantly associated with caregiver burden or self-rated caregiver health.

## Discussion

This study is one of the largest national investigations to date to look at caregiving differences by geographical setting. The results confirm the results of previous reports in suggesting no differences in caregiver burden between rural and urban areas despite socioeconomic disparities, with some studies even supporting a protective factor of rural residence. A 2017 study leveraging the 'Caregiving in the U.S. 2015' National Alliance for Caregiving and American Association of Retired Persons survey showed rural caregivers had lower socioeconomic status than their urban counterparts and did not demonstrate a difference in physical, financial, or emotional burden of caregiving<sup>9</sup>. A larger study from 10 states identified that rural caregivers frequently had greater financial barriers than urban caregivers and were less likely to report any difficulty related to caregiving<sup>6</sup>. A focused study of Pittsburgh caregivers similarly found a protective factor to caregiving<sup>8</sup>.

Previous studies have hypothesized possible reasons for the lack of caregiver burden despite financial inequalities, including a possible greater perceived generativity in rural populations<sup>19</sup>, the use of social comparison where caregivers have an emotional benefit by comparing themselves to those less well off, or increased coping mechanisms that may have developed over time to address multiple life stressors. Additionally, rural caregivers may be underreporting burden as they feel a greater responsibility to care for a family member<sup>8,20</sup>. Finally, although there is an income disparity between metropolitan and non-metropolitan settings, the cost of living is less in rural areas and may buffer some of the disparity<sup>21,22</sup>.

Additionally, the present research might suggest that the presence of a spouse or partner, regardless of their role in the caregiving process, could be one factor in protecting rural caregivers from

burden. Previous research has shown associations of informal social support with lower caregiver burden. However, further investigation would be required to confirm this hypothesis<sup>23</sup>.

In contrast to previous reports, the present study did not identify significant differences in self-reported health status between geographic residence. Other studies have indicated a higher prevalence of chronic conditions and an increased likelihood of reporting poor or fair health in rural communities, although one study only saw significance in a multivariate model rather than a bivariate model<sup>6,8,9,22</sup>. Additionally, there are mixed results for significance of self-reported health on perceived health burden<sup>6,11</sup>. The discrepancy across studies might be due to cohort size, definitions of rural areas, or geographic distributions of sampling. Additional larger studies are necessary to further evaluate the difference.

The NSOC and NHATS studies provide extensive, comprehensive datasets with excellent national representation to create a strong study of caregiver experience. However, the present report has a number of limitations. The publicly available data on residence were restricted to the resolution of 'metropolitan' and 'non-metropolitan'. Future studies would benefit from further subdividing residence by the nine RUCCs to look at more nuanced differences in resource use and caregiver burden, because studies have shown spatial clustering of caregiver features<sup>8</sup>. That said, within the current dataset, only 429 caregivers were from non-metropolitan regions, thus further stratification of the data could be challenging to provide a sample size with enough participants to conduct detailed subgroup analyses. Further, the NSOC data selected caregivers that helped only with daily tasks, transportation, or medical needs. While comprehensive, it would be interesting to include self-reported caregivers regardless of tasks they perform in order to gain a broader representation of the caregiver experience.

This study demonstrates that, despite economic disparities, caregivers self-report no difference in financial burden between urban–rural settings. Future studies should include additional survey questions to better understand the reasons for this dichotomy. In this way, we might be able to learn from the resilience in the rural populations to improve universal caregiver experience.

## Conclusion

This study builds on previous reports to understand geographical differences in the caregiver experience. Leveraging a large national study of 2278 total caregivers (weighted *N* of around 20 million), this study identified similar caregiver experiences across locations

despite disparities in income. However, additional studies that further divide the cohort by population and include larger rural sampling are essential to determine if rural caregivers truly are

thriving despite disparities, and, if so, how communities can learn from them to help all caregivers thrive.

## REFERENCES:

- 1** Ortman JM, Velkoff VA, Hogan H. *An aging nation: the Older Population in the United States. Population Estimates and Projections. Current Population Reports*. 2014. Available: <https://www.census.gov/prod/2014pubs/p25-1140.pdf> (Accessed 7 October 2020).
- 2** Schulz R, Eden J. *Families caring for an aging America*. 2016. Available: <https://www.ncbi.nlm.nih.gov/books/NBK396399/?report=reader> (Accessed 2 April 2020). <https://doi.org/10.17226/23606>
- 3** Gibson Hunt G, Reinhard S, Greene R, Whiting CG, Feinberg LF, Choula R, et al. *Caregiving in the U.S. 2015 Report*. 2015. Available: [https://www.caregiving.org/wp-content/uploads/2020/05/2015\\_CaregivingintheUS\\_Final-Report-June-4\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf) (Accessed 2 April 2020).
- 4** National Alliance for Caregiving and Evercare. *Evercare survey of the economic downturn and its impact on family caregiving*. Available: [http://www.caregiving.org/data/EVC\\_Caregivers\\_Economy\\_ReportFINAL\\_4-28-09.pdf](http://www.caregiving.org/data/EVC_Caregivers_Economy_ReportFINAL_4-28-09.pdf) (Accessed 2 April 2020).
- 5** Freedman VA, Spillman BC. Disability and care needs among older Americans. *Milbank Quarterly* 2014; **92(3)**: 509-541. <https://doi.org/10.1111/1468-0009.12076> PMID:25199898
- 6** Bouldin ED, Shaull L, Andresen EM, Edwards VJ, McGuire LC. Financial and health barriers and caregiving-related difficulties among rural and urban caregivers. *Journal of Rural Health* 2018; **34(3)**: 263-274. <https://doi.org/10.1111/jrh.12273> PMID:28940539
- 7** 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. *International Journal of Older People Nursing* 2015; **10(1)**: 27-37. <https://doi.org/10.1111/opn.12044> PMID:24433340
- 8** Beach SR, Kinnee E, Schulz R. Caregiving and place: combining Geographic Information System (GIS) and survey methods to examine neighborhood context and caregiver outcomes. *Innovation in Aging* 2019; **3(3)**: 1-15. <https://doi.org/10.1093/geroni/igz025> PMID:31528713
- 9** Crouch E, Probst JC, Bennett K. Rural-urban differences in unpaid caregivers of adults. *Rural and Remote Health* 2017; **17(4)**: 4351. Available: <http://www.rrh.org.au/journal/article/4351> (Accessed 31 March 2020). <https://doi.org/10.22605/RRH4351> PMID:29166125
- 10** Smith AS, Trevelyan E. *The older population in rural America: 2012-2016*. 2019. Available: <https://www.census.gov/library/publications/2019/acs/acs-41.html> (Accessed 7 October 2020).
- 11** Riffin C, Van Ness PH, Wolff JL, Fried T. A multifactorial examination of caregiver burden in a national sample of family and unpaid caregivers. *Journal of the American Geriatrics Society* 2019; **67(2)**: 277-283. <https://doi.org/10.1111/jgs.15664> PMID:30452088
- 12** Montaquila J, Freedman VA, Spellman B, Kasper JD. *National Health and Aging Trends Study (NHATS) Technical Paper #1*. Baltimore: Johns Hopkins University School of Public Health, 2012.
- 13** Wolff JL, Spillman BC, Freedman VA, Kasper JD. A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine* 2016; **176(3)**: 372-379. <https://doi.org/10.1001/jamainternmed.2015.7664> PMID:26882031
- 14** United States Department of Agriculture Economic Research Service. *Rural-Urban Continuum codes*. Available: <https://www.ers.usda.gov/data-products/rural-urban-continuum-codes> (Accessed 1 April 2020).
- 15** Löwe B, Wahl I, Rose M, Spitzer C, Glaesmer H, Wingenfeld K, et al. A 4-item measure of depression and anxiety: validation and standardization of the Patient Health Questionnaire-4 (PHQ-4) in the general population. *Journal of Affective Disorders* 2010; **122(1-2)**: 86-95. <https://doi.org/10.1016/j.jad.2009.06.019> PMID:19616305
- 16** Plummer F, Manea L, Trepel D, McMillan D. Screening for anxiety disorders with the GAD-7 and GAD-2: a systematic review and diagnostic metaanalysis. *General Hospital Psychiatry* 2016; **39**: 24-31. <https://doi.org/10.1016/j.genhosppsych.2015.11.005> PMID:26719105
- 17** Kroenke K, Spitzer RL, Williams JBW. The patient health questionnaire-2: validity of a two-item depression screener. *Medical Care* 2003; **41(11)**: 1284-1292. <https://doi.org/10.1097/01.MLR.0000093487.78664.3C> PMID:14583691
- 18** Kasper JD, Freedman VA, Brenda S. *Classification of persons by dementia status in the National Health and Aging Trends Study. Technical paper #5*. Baltimore: Johns Hopkins University School of Public Health, 2013.
- 19** Grossman MR, Gruenewald TL. Caregiving and perceived generativity: a positive and protective aspect of providing care? *Clinical Gerontology* 2017; **40(5)**: 435-447. <https://doi.org/10.1080/07317115.2017.1317686> PMID:28521595
- 20** Stewart TL, Chipperfield JG, Ruthig JC, Heckhausen J. Downward social comparison and subjective well-being in late life: the moderating role of perceived control. *Aging & Mental Health* 2013; **17(3)**: 375-385. <https://doi.org/10.1080/13607863.2012.743963> PMID:23210907
- 21** Kurre JA. Is the cost of living less in rural areas? *International Regional Science Review* 2003; **26(1)**: 86-116. <https://doi.org/10.1177/0160017602238987>
- 22** Douthit N, Kiv S, Dwolatzky T, Biswas S. Exposing some important barriers to health care access in the rural USA. *Public Health* 2015; **29**: 611-620. <https://doi.org/10.1016/j.puhe.2015.04.001> PMID:26025176

**23** Shiba K, Kondo N, Kondo K. Informal and formal social support and caregiver burden: the AGES caregiver survey. *Epidemiology* 2016; **26(12)**: 622-628. <https://doi.org/10.2188/jea.JE20150263> PMID:27180934  
Supplementary material is available on the live site <https://www.rrh.org.au/journal/article/6062/#supplementary>

This PDF has been produced for your convenience. Always refer to the live site <https://www.rrh.org.au/journal/article/6062> for the Version of Record.