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BRIEF REPORT

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Geographic disparities in unpaid caregiving

Emma Kathryn Boswell MPH[1] | **Monique J. Brown PhD**[2] | **Lorie Donelle PhD**[3] | **Nicholas Yell PhD**[1] | **Taryn Farrell MPH**[1] | **Peiyin Hung PhD**[1] | **Elizabeth Crouch PhD**[1]

[1]University of South Carolina Rural Health Research Center, Arnold School of Public Health, University of South Carolina, Columbia, South Carolina, USA

[2]Department of Epidemiology and Biostatistics, Arnold School of Public Health, University of South Carolina, Columbia, South Carolina, USA

[3]Department of Biobehavioral Health & Nursing Science, College of Nursing, University of South Carolina, Columbia, South Carolina, USA

Correspondence
Emma Kathryn Boswell, MPH, University of South Carolina Rural Health Research Center, Arnold School of Public Health, University of South Carolina, 220 Stoneridge Dr. Suite 204 Columbia, SC 29210.
Email: emmakb@email.sc.edu

Abstract

Purpose: An updated, nationally representative examination of rural–urban differences in the experiences, health, and well-being of caregivers is needed; previous research on this topic uses older data or has limited generalizability. This study examines rural–urban differences in the characteristics, experiences, and health of caregivers.

Methods: The 2021–2022 Behavioral Risk Factor Surveillance System (n = 44,274 unpaid caregivers) was used, with rurality defined according to the 2013 National Center for Health Statistics (NCHS) Urban-Rural Classification Scheme. Chi-square tests compared rural–urban differences in these caregivers' characteristics, including demographic factors, caregiving intensity (e.g., weekly hours spent caregiving, reason for caregiving, past-month ADL/IADL assistance), caregiver's health (e.g., general health status and past month physical health, mental health, and limited activity), and caregiver's health behavior (chronic illness, smoking status, binge drinking, and annual checkups).

Findings: Compared to urban caregivers, rural caregivers were more likely to have at least one chronic condition (58.3% vs. 53.2%; $p < 0.0001$), be obese (42.9% vs. 37.5%; $p < 0.0001$), be a smoker (24.2% vs. 15.5%; $p < 0.0001$), and less likely to be a binge drinker (12.7% vs. 15.3%; $p = 0.003$). Compared to urban caregivers, rural caregivers were more likely to report their general health status as fair/poor (20.3% vs. 17.0%, $p = 0.0003$) and were more likely to report 14 or more days of poor physical health in the past month (15.6% vs. 12.0%, $p < 0.0001$).

Conclusions: Understanding geographic disparities in the experiences and context of unpaid caregiving is needed to improve their overall well-being and health. Future research will be necessary to determine factors associated with these outcomes.

KEYWORDS
informal caregiving, rural–urban disparities, quality of life

INTRODUCTION

In 2020, more than one in five Americans, or approximately 53 million adults, reported providing care to an adult or child with special needs in the past year.[1] In the coming decades, both the proportion of elderly adults in the US population and the prevalence of chronic disease in older adults is expected to increase.[2,3] These shifts correspond with a strong need for caregiving; approximately 25% of US adults aged 65 or older will require significant support for at least 3 years.[4] Additionally, more than 75% of older Americans want to age in place.[5] The costs of formal caregiving, including home health care, nursing home care, and continuing care communities are on the rise, which may make formal caregiving less feasible or less accessible to many Americans.[6] Due to personal preferences and the financial costs of formal caregiving, much of the needed caregiving is expected to be informal or unpaid caregiving from friends and family members.[7]

A disproportionate number of elderly adults live in rural areas in the United States, meaning that the need for unpaid caregiving is particularly great in rural communities.[8] The prevalence of unpaid caregiving is higher in rural areas, possibly because of demographic differences between rural and urban communities, stronger feelings of family obligation among rural populations, or higher poverty rates in rural areas.[9,10] The experiences of unpaid caregivers (herein caregivers) differs between rural and urban communities; rural caregivers are more likely to care for more than one person, to report that they did not have a choice in taking on their caregiving role, and to report financial strain than urban caregivers.[1,11] A previous study examining caregiving burden found that there were no statistically significant rural–urban differences in health status; conversely, other research has shown that when compared to urban caregivers, rural caregivers were more likely to have worse general, physical, and mental health.[12–14] Rural caregivers also face unique challenges due to issues such as lack of access to care, lack of support or respite services, or higher levels of poverty.[15–17]

An updated, nationally representative examination of rural–urban differences in the experiences, health, and well-being of caregivers is needed; previous research on this topic uses much older data or is limited in generalizability due to small sample sizes (example: three states with a sample size of approximately 15,000 caregivers) or study design.[11–14] Therefore, this report seeks to provide an update on rural–urban differences in the sociodemographic characteristics, experiences, and health of caregivers using 2 years (2021–2022) of the Behavioral Risk Factor Surveillance System (BRFSS). Understanding geographic disparities in the experiences and well-being of caregivers will be helpful in the development and implementation of interventions and educational programs aimed at improving their overall health.

METHODS

Data source and population

This study uses data from the 2021–2022 BRFSS, an annual, nationally representative, cross sectional survey that examines self-reported health and health behaviors.[18] BRFSS participants are from all US states, territories, and Washington, DC, and the sample design and weighting utilized by BRFSS ensure that it is nationally representative of the adult non-institutionalized US population.[18] BRFSS consists of three main sections; the core module is used by all states and territories, the optional modules that states can choose to participate in, and the state-specific questions, which are developed and administered by the states themselves.[19,20] In 2021–2022, 47 unique states participated in the caregiver module, which asks unpaid caregivers questions about their experiences with caregiving.[21–23] Of these 47 states, 39 participated in 2021, 14 participated in 2022, and 6 states participated in both years.[21,22]

This study's sample included participants who lived in a state that administered the caregiving module during the study period, self-identified as being a caregiver, and had non-missing responses for all relevant variables. If a person responded yes when asked, "During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?," then they were considered to be an unpaid caregiver.[24,25] The main analytic sample consisted of 44,274 unpaid caregivers.

Measures

The independent variable for this report is rurality. Rurality was classified at the county level using the 2013 National Center for Health Statistics (NCHS) Urban-Rural Classification Scheme.[24,25] BRFSS provides a dichotomous rural–urban variable; participants were classified as living in a rural county if they lived in a micropolitan or non-core county, or as living in an urban county if they lived in a large central metro, large fringe metro, medium metro, or small metro county.[24,25]

The dependent variables for this report are caregiving attributes and the health and well-being of caregivers. Caregiving attributes were the relationship between the caregiver and care recipient, length of time spent the caregiver has acted in a caregiving role, weekly hours spent caregiving, reason the care recipient is receiving caregiving, if the care recipient had an additional Alzheimer's or dementia diagnosis, whether the caregiver assisted with activities of daily living (ADLs), and whether the caregiver assisted with instrumental activities of daily living (IADLs). The relationship between the caregiver and care recipient was categorized according to the age of the recipient relative to the caregiver and was classified as peer (recipient was the sibling, sibling-in-law, spouse, or partner of the caregiver), elder (recipient was the parent, parent-in-law, or grandparent of the caregiver), younger (recipient was the child or grandchild of the caregiver) or other (relative was unknown- recipient was described as "other relative" or "non-relative").

The well-being of caregivers was measured using the caregiver's health, health behaviors, and health-related quality of life (HRQoL). Health and health behavior variables included the number of chronic health conditions, obesity status, smoking status, binge drinking status, and whether the participant had missed their last annual checkup. HRQoL measures included the general health status of the caregiver, whether the caregiver experienced poor physical health in the past

month, whether the caregiver experienced poor mental health in the past month, and whether the caregiver had to limit their usual activity in the past month. Participants were identified as having poor health or limited activity in the past month if they self-reported having poor health or limited usual activity on at least 14 days during the thirty days before the date they participated in the BRFSS survey.

Covariates for this study included survey year, race/ethnicity, sex, age, educational attainment, marital status, annual household income, employment status, insurance status, and the presence of children in the caregiver's household. For all variables, if participants refused to respond or responded "I don't know," they were treated as missing and excluded from analysis ($n = 9{,}719$).

Analyses

Analyses were conducted using SAS 9.4 © and followed the prescribed guidelines for weighting to ensure that the study was representative.[19,20] An alpha value of 0.05 was used for all analyses. To evaluate rural/urban differences in sociodemographic characteristics, caregiving attributes, health/health behaviors, and HRQoL, bivariate analyses via Rao-Scott chi-square tests were conducted. This report was approved as not human subjects research by the [blinded] Institutional Review Board.

RESULTS

A total of 44,274 unpaid caregivers were evaluated in this report, 14,460 (32.7%) of which lived in a rural county (see Table 1). Most participants took part in BRFSS in 2021 (86.1%), and there was a slight but statistically significant difference in the proportion of rural and urban residents (in 2021, 84.5% vs. 86.5%, $p < 0.0001$). Compared to urban caregivers, rural caregivers tended to be non-Hispanic White (81.7% vs. 64.5%, $p < 0.0001$), older (27.4% vs. 21.1% were aged 65 or older, $p < 0.0001$), have lower educational attainment (7.7% vs. 10.8% have less than a high school degree, $p < 0.0001$), be part of a married/unmarried couple (62.0% vs. 64.2%, $p < 0.0001$), have a lower annual household income (15.6% vs. 21.1% had an annual household income of <$25,000, $p < 0.0001$), be unemployed (34.7% vs. 31.7%, $p = 0.003$), be publicly insured (35.7% vs. 47.7%, $p < 0.0001$), and to not have children at home (65.3% vs. 68.3%, $p = 0.02$). Approximately 60% of unpaid caregivers were female.

There were no significant rural–urban differences in caregiving attributes (see Table 2). Most caregivers, both rural and urban, were caring for an elder (42.8%), for a person who had a chronic illness (25.0%) or had a condition listed as "other" (33.0%), and for a person who did not have an additional Alzheimer's diagnosis (85.8%). Approximately 30% of all caregivers had been caregiving for five or more years, and a little more than half (54.2) spent eight or less hours per week caregiving. Around half (52.0%) of both rural and urban caregivers provided ADL assistance in the past month, and more than 80% had provided IADL assistance in the past month (Table 3).

There were significant rural–urban disparities in the health/health behavior and HRQoL of unpaid caregivers. Compared to urban caregivers, rural caregivers were more likely to be obese (37.5% vs. 42.9%, $p < 0.0001$), to be a current smoker (15.5% vs. 24.2%, $p < 0.0001$), and were less likely to be a binge drinker (15.3% vs. 12.7%, $p = 0.003$) or to have no chronic conditions (46.8% vs. 41.8%, $p < 0.0001$). Rural unpaid caregivers were less likely to have missed their most recent annual checkup than urban caregivers ($p = 0.01$). Compared to urban caregivers, rural caregivers were more likely to report their general health status as fair or poor (17.0% vs. 20.3%, $p = 0.0003$), and were more likely to report 14 or more days of poor physical health in the past month (12.0% vs. 15.6%, $p < 0.0001$). There were no significant rural–urban differences in past month poor mental health or limited usual activity.

DISCUSSION

This study provides a needed update to the literature describing national rates of unpaid caregiving by rurality, as this study includes 47 states and over 44,000 unpaid caregivers, while earlier research included only three states and just over 15,000 caregivers or used older data.[12,14] This study found that despite there being no significant rural–urban differences in caregiving attributes, such as time spent caregiving or type of care being provided, rural caregivers are more likely to report their general and physical health as poor. This study also found that rural caregivers were more likely to report being obese and being a smoker and were less likely to report binge drinking, unlike previous research, which found no significant difference.[12] The higher prevalence of poor general and physical health among rural caregivers despite the lack of differences in caregiving attributes may be due to poorer health behaviors among this population, such as smoking, or because rural caregivers are generally less educated, more impoverished, and older, which have been shown to be predictors of poor health among non-caregivers.[26]

Currently, every state provides some level of funded respite care through Medicaid, but eligibility and levels of assistance vary by state.[27] Due to the sociodemographic differences in rural and urban caregivers, policies and programs designed to assist caregivers may need different educational and respite components for rural versus urban caregivers. Prior literature has noted that rural caregivers face additional challenges when caregiving, including lack of resources, knowledge about available resources, and lack of health literacy.[15,16] Additionally, previous research has noted that rural caregivers of color are less likely to use respite services and may face unique barriers, such as provider discrimination and limited English proficiency, when caregiving.[15,17]

There are several limitations to this study, all BRFSS data is self-reported and not confirmed by any further investigation such as laboratory testing or medical record, and thus subject to recall and social desirability bias.[19,20] Causality cannot be determined with cross-

TABLE 1 Sociodemographic characteristics of unpaid caregivers in 2021–2022 BRFSS ($n = 44,274$).

Characteristic	Overall ($n = 44,274$) *N* (%)	Rural ($n = 14,460$) *N* (%)	Urban ($n = 29,814$) *N* (%)	*p* Value
Survey year				<0.0001
2021	30,759 (86.1)	10,702 (84.5)	20,057 (86.5)	
2022	13,515 (13.9)	3758 (15.5)	9757 (13.5)	
Race/ethnicity				<0.0001
NH White	35,268 (67.4)	12,115 (81.7)	23,153 (64.5)	
NH Black	3538 (12.0)	786 (8.3)	2752 (12.7)	
Hispanic	2524 (12.6)	497 (4.5)	1927 (14.3)	
NH Other	3044 (8.0)	1062 (5.5)	1982 (8.5)	
Sex				0.66
Male	16,890 (39.6)	5384 (40.1)	11,506 (39.5)	
Female	27,384 (60.4)	9076 (59.9)	18,308 (60.5)	
Age				<0.0001
18–44 years	10,214 (36.8)	2974 (33.3)	7240 (37.5)	
45–64 years	19,137 (41.1)	6131 (39.4)	13,006 (41.4)	
65+ years	14,923 (22.2)	5355 (27.4)	9568 (21.1)	
Educational attainment				<0.0001
Less than high school	1651 (8.2)	667 (10.8)	984 (7.7)	
High school graduate	9820 (25.0)	3836 (31.9)	5984 (23.6)	
Some college	13,836 (35.7)	4753 (36.3)	9083 (35.6)	
College graduate	18,967 (31.1)	5204 (20.9)	13,763 (33.1)	
Marital status				<0.0001
Married/unmarried couple	28,214 (62.4)	9453 (64.2)	18,761 (62.0)	
Divorced/separated	6872 (13.7)	2200 (14.0)	4672 (13.6)	
Widow/widower	3266 (5.4)	1196 (6.9)	2070 (5.1)	
Never been married	5922 (18.5)	1611 (14.9)	4311 (19.3)	
Annual household income				<0.0001
< $25,000	6688 (16.6)	2612 (21.1)	4076 (15.6)	
$25,000–49,999	12,024 (25.6)	4527 (33.6)	7497 (23.9)	
$50,000–74,999	8201 (17.1)	2808 (18.2)	5393 (16.8)	
≥ $75,000	17,361 (40.8)	4513 (27.1)	12,848 (43.6)	
Employment status				0.003
Employed	23,330 (56.2)	7250 (52.9)	16,080 (56.8)	
Unemployed	20,944 (43.8)	7210 (47.1)	13,734 (43.2)	
Insurance status				<0.0001
Private	21,212 (52.4)	6209 (44.6)	72,505 (56.4)	
Public	21,055 (41.2)	7512 (47.7)	57,085 (35.7)	
None	2007 (6.4)	739 (7.7)	6568 (7.8)	
Children living at home				0.02
Yes	11,638 (34.2)	3584 (31.7)	8054 (34.7)	
No	32,636 (65.8)	10,876 (68.3)	21,760 (65.3)	

TABLE 2 Rural–urban differences in caregiving attributes in 2021–2022 BRFSS ($n = 44,274$).

Caregiving attributes	Overall ($n = 44,274$) N (%)	Rural ($n = 14,460$) N (%)	Urban ($n = 29,814$) N (%)	p Value
Relationship between caregiver and recipient				0.11
Peer	12,578 (25.2)	4411 (27.8)	8167 (24.7)	
Younger	4698 (11.1)	1436 (10.7)	3262 (11.1)	
Elder	17,250 (42.8)	5345 (41.3)	11,905 (43.1)	
Other	9748 (20.9)	3268 (20.3)	6480 (21.0)	
Length of caregiving				0.15
< 6 months	12,077 (28.0)	3893 (25.8)	8184 (28.5)	
6 months to 2 years	8630 (18.9)	2853 (20.2)	5777 (18.6)	
2–4 years	9985 (22.6)	3287 (23.2)	6698 (22.4)	
≥ 5 years	13,582 (30.5)	4427 (30.7)	9155 (30.5)	
Weekly hours spent caregiving				0.051
≤8 h	24,357 (54.2)	7988 (51.9)	16,369 (54.6)	
9–19 h	6472 (14.6)	2075 (15.0)	4397 (14.5)	
20–39 h	5225 (11.8)	1734 (13.0)	3491 (11.5)	
≥ 40 h	8220 (9.4)	2663 (20.1)	5557 (19.3)	
Reason recipient is receiving caregiving				0.74
Cancer	3502 (8.4)	1125 (7.1)	2377 (8.7)	
Chronic illness[a]	10,560 (25.0)	3716 (27.4)	6844 (24.6)	
Mental or behavioral health concern[b]	4183 (10.4)	1215 (9.9)	2968 (10.5)	
Old age/infirmity/frailty	6464 (12.9)	2167 (13.3)	4297 (12.9)	
Cognitive impairment disorder[c]	4871 (10.1)	1475 (9.3)	3396 (10.3)	
Other[d]	14,694 (33.0)	4762 (33.0)	9932 (33.1)	
Recipient has additional Alzheimer's diagnosis				0.84
Yes	5792 (14.2)	1888 (14.4)	3904 (14.2)	
No	33,611 (85.8)	11,097 (85.6)	22,514 (85.8)	
Past month ADL[e] assistance				0.09
Yes	21,934 (52.0)	7023 (52.2)	14,911 (52.0)	
No	22,340 (48.0)	7437 (47.8)	14,903 (48.0)	
Past month IADL[f] assistance				0.11
Yes	35,929 (81.0)	11,663 (82.6)	24,266 (80.7)	
No	8345 (19.0)	2797 (17.4)	5548 (19.3)	

[a]Includes asthma and Chronic respiratory conditions such as emphysema or COPD.[24,25]
[b]Includes Alzheimer's disease, dementia, or other related cognitive impairment disorder.[24,25]
[c]Includes diabetes, heart disease, hypertension, stroke, and other organ failure or diseases such as kidney or liver problems.[24,25]
[d]Includes Spina Bifida, Autism, Down's Syndrome, and similar conditions.[24,25]
[e]Activities of daily living; includes managing personal care such as giving medications, feeding, dressing, or bathing.[24,25]
[f]Instrumental activities of daily living; includes managing household tasks such as cleaning, managing money, or preparing meals.[24,25]

sectional data. Strengths of the study include the most up to date caregiving data and with the largest swathe of states, to provide a timely and relevant analysis for policymakers. In the publicly available BRFSS data sets, only dichotomous levels of rurality are available.[24,25] This may obscure differences in the lived experiences of caregivers that vary across levels of rurality. Future research should attempt to utilize a more granular measure of rurality to better explore these differences. This study is extremely valuable for members of rural communities, as it allows policy makers to better understand the landscape of caregiving amongst minoritized rural residents and help program developers design and implement initiatives for rural caregivers.[28]

TABLE 3 Rural–urban differences in the health and well-being of unpaid caregivers.

Outcome	Overall ($n = 44,274$) *N* (%)	Rural ($n = 14,460$) *N* (%)	Urban ($n = 29,814$) *N* (%)	*p* Value
Health/health behavior				
Number of chronic conditions				<0.0001
None	18,342 (46.0)	5848 (41.8)	12,494 (46.8)	
1	14,014 (30.9)	4599 (31.3)	9415 (30.8)	
2 or more	11,918 (23.2)	4013 (27.0)	7905 (22.4)	
Has obesity				<0.0001
Yes	16,904 (38.5)	5828 (42.9)	11,076 (37.5)	
No	27,370 (61.5)	8632 (57.1)	18,738 (62.5)	
Currently smokes				<0.0001
Yes	7102 (17.0)	2637 (24.2)	4465 (15.5)	
No	37,172 (83.0)	11,823 (75.8)	25,349 (84.5)	
Binge drinker				0.003
Yes	5641 (14.9)	1679 (12.7)	3962 (15.3)	
No	38,633 (85.1)	12,781 (87.3)	25,852 (84.7)	
Missed annual health checkup				0.01
Yes	8520 (23.6)	2722 (21.2)	5798 (24.1)	
No	35,754 (76.4)	11,738 (78.8)	24,016 (75.9)	
Health-related quality of life				
General health status				0.0003
Good, very good, or excellent	36,671 (82.4)	11,716 (79.7)	24,955 (83.0)	
Fair or poor	7603 (17.6)	2744 (20.3)	4859 (17.0)	
Past month poor physical health[a]				<0.0001
Yes	38,399 (87.4)	2055 (15.6)	3820 (12.0)	
No	5875 (12.6)	12,405 (84.4)	25,994 (88.0)	
Past month poor mental health[b]				0.67
Yes	7671 (19.7)	2415 (20.1)	5256 (19.6)	
No	36,603 (80.3)	12,045 (79.9)	24,558 (80.4)	
Past month limited usual activity[c]				0.10
Yes	4646 (11.3)	1562 (12.5)	3084 (11.0)	
No	39,628 (88.7)	12,898 (87.5)	26,730 (89.0)	

[a]Reported poor physical health for at least 14 days in the past month.[24,25]
[b]Reported poor mental health for at least 14 days in the past month.[24,25]
[c]Poor physical or mental health prevented participants from participating in their usual activities (such as self-care, work, or recreation) for at least 14 days in the past month.[24,25]

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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DATA AVAILABILITY STATEMENT

Data is publicly available for download from the CDC's Behavioral Risk Factor Surveillance Survey.

ETHICS STATEMENT

Informed consent was not required as this study was based on publicly available data. The Institutional Review Board at the University of South Carolina approved this research.

ORCID

Emma Kathryn Boswell MPH https://orcid.org/0009-0006-3704-1182
Peiyin Hung PhD https://orcid.org/0000-0002-1529-0819
Elizabeth Crouch PhD https://orcid.org/0000-0002-5380-8391

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