



Published: December 31, 2023

Citation: Kent EK, Aimone, et al., 2023. Unmet Support Service Needs Among Rural Family Caregivers: A Population-Based U.S. Study, *Medical Research Archives*, [online] 11(12). <https://doi.org/10.18103/mra.v11i12.4854>

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DOI

<https://doi.org/10.18103/mra.v11i12.4854>

ISSN: 2375-1924

RESEARCH ARTICLE

Unmet Support Service Needs Among Rural Family Caregivers: A Population-Based U.S. Study

Erin E. Kent, PhD, MS^{*1-3}, Elizabeth Aimone, MS², Maija Reblin, PhD⁴, Shakira J. Grant, MBBS, MSCR^{2, 5}, Lixin Song, PhD, RN, FAAN^{2, 6}, Madeline R. Sterling, MD, MPH, MS⁷, Yiqing Qian, PhD, MPH⁸, Eliza M. Park, MD, MSc²

1. Department of Health Policy and Management, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC
2. Lineberger Comprehensive Cancer Center, University of North Carolina at Chapel Hill, Chapel Hill, NC
3. Cecil G. Sheps Health Services Research Center, University of North Carolina at Chapel Hill, Chapel Hill, NC
4. Department of Family Medicine, Larner College of Medicine, University of Vermont, Burlington, VT
5. Department of Medicine, Division of Hematology and Division of Geriatrics, University of North Carolina at Chapel Hill, Chapel Hill, NC
6. School of Nursing, University of Texas Health Science Center at San Antonio, San Antonio, TX
7. Department of Medicine, Weill Cornell Medicine, New York, NY
8. Center for Equity in Aging, School of Nursing, Johns Hopkins University, Baltimore, MD; Department of Psychiatry and Department of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC

*Corresponding author: erin.kent@unc.edu

ABSTRACT

Background: In rural communities around the world, individuals with serious health problems and their family caregivers often experience greater barriers to healthcare access. Identifying unmet support service needs of rural-dwelling caregivers can reveal intervention and policy targets. We examined unmet needs reported by rural caregivers in the U.S.

Methods: We used data from the 2015-2018 U.S. Behavioral Risk Factor Surveillance System that included the optional caregiving module (32 U.S. states, D.C. and Puerto Rico). We identified rural caregivers using metropolitan statistical area (rural) and the item, "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?" Logistic regression models incorporating sampling weights provided adjusted odds ratios (adjusted ORs) of factors associated with having any unmet support service needs, and specific need types: classes about giving care, help with service access, support groups, individual counseling, respite. Factors included sociodemographic (gender, race/ethnicity, age, education, income, employment, marital status) and caregiving-related (intensity [\pm 20 hours/week and \pm 2-year duration], caregiver-care recipient relationship, and main health problem) variables.

Results: Of the 8,651 rural caregivers (representing 2.3 million) included, 16% endorsed unmet needs. Help accessing services was the most common need, followed by support groups and individual counseling. Factors associated with higher odds of any unmet need included Black vs. White race (adjusted OR: 1.74 [95%CI: 1.21-2.50]), college vs. high school graduate (adjusted OR: 1.85 [1.37-2.52]), and higher vs. lower intensity caregiving (adjusted OR: 2.18 [1.27-3.73]).

Conclusions: Many U.S. rural caregivers report unmet support service needs. Future interventions to benefit rural caregivers should target individuals and communities with the highest unmet needs.

Introduction

Family caregivers provide essential support to individuals living with serious illnesses and disabilities. These family members and friends provide wide-ranging care and support that helps their care recipients remain at home and in their communities. In the U.S., according to 2015 data, about 12% of caregivers live in rural communities, a percentage that has decreased from 16% when previously collected in 2015.¹ Rural residents are more likely to be caregivers than non-rural residents, and they are more likely to provide a higher number of hours (>20 hours per week), according to data analyzed from the 2018 Behavioral Risk Factor Surveillance Study (BRFSS).² However, rural caregivers report additional challenges compared to their urban counterparts. In rural vs. urban areas in the U.S., caregivers are more likely to be White, married, and report two or more chronic health conditions themselves.³ Caregivers in rural communities are experiencing reduced investment in public health systems,⁴ persistent barriers to healthcare access and social services,⁵ and increasing rural hospital closures.⁶

Rural caregivers experience a high burden of care relative to their urban counterparts. While rural residents are more likely to indicate that they are caregivers, they are also less likely to indicate that they share caregiving responsibilities with direct care workers, including home health aides.⁷ Rural caregivers are more likely to provide care for significantly longer hours during the week (20 or more) than non-rural caregivers.² Rural caregivers report more financial strain, longer travel times for care, and lower use of professional support services.³ In a recent Canadian study, 2/3 of rural caregivers reported experiencing social loneliness, or the perceived absence of a broader social network.⁸ Lastly, a growing number of rural caregivers report having no choice in taking on caregiving responsibilities (51% in 2020, up from 43% in 2015).¹

The barriers that rural residents in general and caregivers specifically face stem from the constraints on health played by that several social determinants of health, including transportation, housing, employment opportunities, education, and more.⁹ In 2022, the U.S. Centers for Medicare and Medicaid Services published a framework for advancing health care in rural, tribal, and geographically isolated communities¹⁰ The framework listed several opportunities, including increasing the the collection and use of standardized data to improve healthcare for rural populations. This charge, along with previous empirical findings that suggest large unmet support service needs among rural caregivers, provides

rationale for the current analyses. To date, there is limited research to identify the most pressing concerns to help target care delivery and policy solutions.^{11,12} In this study, we examine factors related to unmet support service needs among American rural caregivers in a large, population-based study. Previous research supports hypotheses that rural caregivers with lower educational attainment and lower income, identifying as Black (as compared to White), and those with higher intensity caregiving responsibilities would be more likely to report unmet support needs. We set out to test these hypotheses to inform future practice and policy development for rural caregivers.

Methods

DATA COLLECTION

We used a descriptive cross-sectional study design and data from the Behavioral Risk Factor Surveillance System for the 32 U.S. states and areas (including D.C. and Puerto Rico) participating in the caregiving module across the years 2015-2018.^{13,14} Respondents were included in the analytic sample if they resided in a rural area as compared to an urban area, according to the Metropolitan Statistical Area (MSA) indicator.¹⁵ The MSA indicator provides a clear definition of urban areas, and for this study, participants were considered rural residents if they lived in a non-MSA-defined urban area. Identification continued by evaluating the response to the question, "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?" Caregivers who responded 'yes' to providing care were included in our analyses.

To evaluate unmet support needs, respondents who identified as caregivers were asked, "Which support do you MOST need that you are not getting?" and were provided the following options: a) classes about giving care, such as giving medications, b) help in getting access to services, c) individual counseling to help cope with giving care, d) respite care, and e) you don't need any of these support services (choose only one answer). Additional covariates from the survey included sociodemographic information referring to current status (gender, race, age, education, income, employment status, marital status), caregiving-related intensity (\pm 20 hours/week and \pm 2-year duration), caregiver-care recipient relationship, and main care recipient's health problem.

DATA ANALYSIS

Using logistic regression models that incorporated sampling weights designated by BRFSS, we generated adjusted odds ratios (adjusted ORs) of

factors associated with unmet support service needs adjusting for sociodemographic factors, caregiving-related intensity, caregiving-care recipient relationship, and main care recipient health condition. Two models were built to examine variables associated with odds of having any unmet needs (binomial logistic regression) and odds of having specific unmet needs vs. no needs (multinomial logistic regression). Listwise deletion was used on missing data for variables that had <10% missing; a missing level was included for variables with ≥10% missing or unknown values (household income). Analyses were run on SAS-Callable SUDAAN v. 11.0.3 (Cary, NC) to examine the relative associations that have been empirically shown to be associated with unmet needs among

caregivers, including sociodemographic and caregiving-related variables.

Results

Of the 8,651 rural caregivers sampled, representing a population base of 2.3 million, over half of the sample identified as female (59%), two-thirds were married, and 28% were over the age of 65 (Table 1). The sample was predominantly White (85%), with the remaining participants identified as Black (9%) or another race (6%). Half reported their educational attainment as a high school degree or less (49%), and 52% reported earnings of less than \$50,000 annually. In addition to their role as a caregiver, 43% of respondents reported working for pay.

Table 1. Descriptive characteristics of caregivers in BRFSS 2015-2018, n=8651

Characteristic	Frequency	Weighted %	
		Estimate	95% CI
Age			
18-34	529	13.4	(11.8, 15.2)
35-44	749	13.4	(11.9, 15.0)
45-54	1359	18.7	(17.2, 20.3)
55-64	2594	26.0	(24.5, 27.6)
65+	3345	27.9	(26.4, 29.4)
Gender			
Female	5748	58.6	(56.6, 60.5)
Male	2684	35.8	(33.9, 37.8)
Race			
White, Non-Hispanic	6903	84.6	(83.3, 85.9)
Black, Non-Hispanic	720	8.5	(7.5, 9.7)
Other, including Hispanic	909	5.8	(5.1, 6.6)
Educational Attainment			
Graduated high school or less	3415	49.2	(47.2, 51.1)
Attended some college or technical school	2727	34.6	(32.7, 36.4)
Graduate college, technical school, and beyond	2492	16.1	(15.0, 17.2)
Household Income			
Less than \$15,000	857	9.9	(8.9, 11.1)
\$15,000 to less than \$25,000	1429	18.2	(16.7, 19.9)
\$25,000 to less than \$35,000	948	10.7	(9.6, 11.9)
\$35,000 to less than \$50,000	1161	13.4	(12.1, 14.7)
\$50,000 or more	2848	31.4	(29.6, 33.2)
Employment Status			
Working	3588	43.3	(41.4, 45.3)
Not-Working	1941	28.8	(27.0, 30.7)
Retired/Unknown	3084	27.2	(25.7, 28.7)
Currently married or partnered			
Yes	5410	67.1	(65.2, 69.0)
No	3213	32.7	(30.8, 34.5)
Children at home			
None	6841	70.8	(68.8, 72.7)
1+	1799	29.1	(27.2, 31.1)
Census Region			
Midwest	1986	23.7	(22.1, 25.4)
Northeast	106	6.4	(5.0, 8.0)
South	3849	54.6	(52.6, 56.5)
West	2710	15.3	(14.2, 16.5)

Note: weighted % may not sum to 100 due to missing data: Age, n=75; Gender, n=219; Race, n=119; Educational attainment, n=17; Income, n=1408; Employment status, n=38; Marital/partner status, n=28; Children at home, n=11.

Table 1. Descriptive characteristics of caregiving in BRFSS 2015-2018, n=8651

Characteristic	Frequency	Weighted %	
		Estimate	95% CI
Relationship to care recipient			
Parents/ parents-in-law	2593	32.3	(30.5, 34.2)
Spouse/partner	1708	17.9	(16.7, 19.2)
Child	639	8.6	(7.6, 9.8)
Another relative	1526	19.6	(18.0, 21.2)
Friend or non-relative	1227	11.9	(10.7, 13.2)
Caregiving Intensity			
High hours, long duration	1248	16.9	(15.5, 18.4)
High hours, short duration	577	6.6	(5.7, 7.6)
Low hours, long duration	2540	28.8	(27.2, 30.6)
Low hours, short duration	3022	32.6	(30.8, 34.4)
Main health problem requiring care			
Dementia/Alzheimer's	628	7.3	(6.4, 8.3)
Cancer	815	8.8	(7.9, 9.9)
Diabetes, cardiovascular disease, hypertension	1210	13.9	(12.7, 15.20)
Other	5598	65.1	(63.3, 66.9)
Personal care			
Yes	4243	50.8	(48.9, 52.7)
No	4326	48.0	(46.0, 49.9)

Note, weighted % may not sum to 100 due to missing data: Relationship to care recipient, n=958; Caregiving intensity, n=1264; Main health problem requiring care, n=400; Provided personal care, n=82.

A total of 16% of the rural caregivers endorsed unmet support service needs. Among those endorsing unmet support needs, the most cited unmet need was the need for help accessing services (7.7% of the total sample). The next most

common unmet needs were desiring support groups (2.7%), individual counseling (2.1%), respite care (2.0%), and classes about giving care (1.5%) (Figure 1).

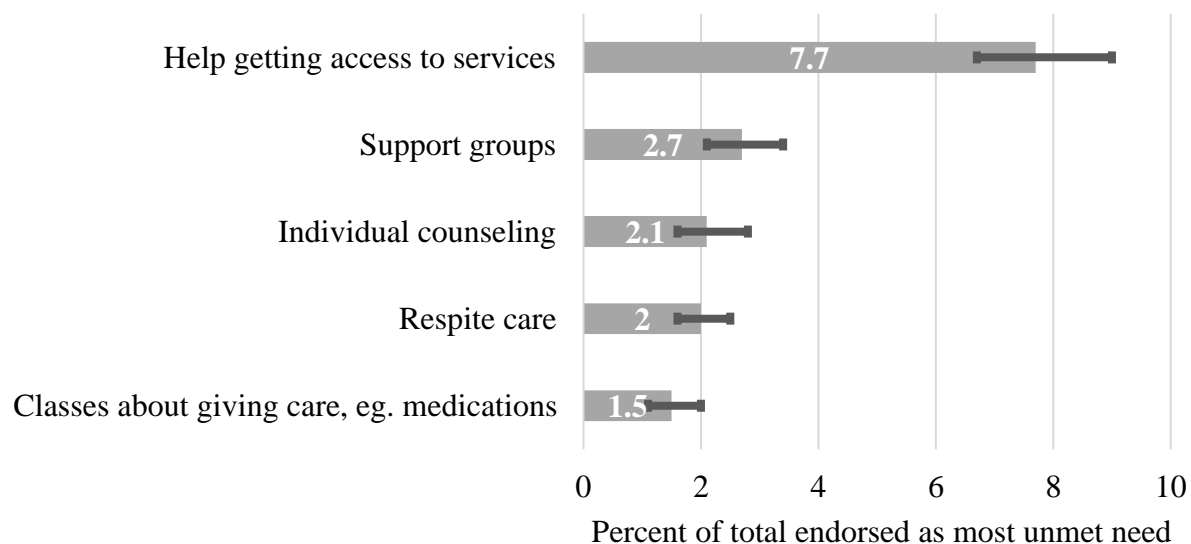


Figure 1. Percent endorsements of most unmet supports and services for rural caregivers for those who endorse having an unmet need, BRFSS 2015-2018. Note: endorsement was limited to only one unmet need.

A fully adjusted logistic regression model yielded the factors significantly associated with unmet support needs (Table 2). For this analysis, 6,189 individuals contributed data. One factor associated with higher odds of any unmet need included self-identification as Black race (adjusted OR: 1.74 [95%CI: 1.17-2.46]), as compared to those who self-identified as White. In addition, college graduation was associated with higher odds of any unmet need when compared to high school graduates (adjusted OR: 1.85 [95%CI: 1.30-2.48]). Lastly, higher hours/shorter duration (<2 years) caregiving demands were associated with higher odds of unmet needs compared to lower intensity caregiving responsibilities (adjusted OR: 2.18 [95%CI: 1.26-3.79]).

The multinomial logistic regression models revealed additional factors associated with specific unmet needs. Respite care needs had the highest number of associated factors, including the following: caregiver age over 65, educational attainment beyond high school, income between 15-25,000 USD vs. lower, not working, caring for parents/parents in laws or children vs. a spouse or partner, providing higher intensity care, and providing personal care. Additional selected associated factors are highlighted here in the text, and the remaining associations are available in Table 2. The reference value reported for each model was reporting no unmet support service need. Men vs. women were more likely to report wanting classes about giving care (adjusted OR: 2.55 [95%CI: 1.15, 5.69]). Caregivers over the age of 65 vs. those under 44 were more likely to report respite care needs (adjusted OR: 6.30 [95%CI: 1.84, 21.63]). Black vs. Non-Hispanic White caregivers were more likely to report wanting classes about giving care (adjusted OR: 5.13 [95%CI: 2.12, 12.45]), help getting access to services (adjusted OR: 1.61 [95%CI: 1.03, 2.51]), and support groups (adjusted OR: 2.13 [95%CI: 1.16, 4.60]). Higher educated (> high school) caregivers were more likely to report individual counseling (attended some college adjusted OR: 2.36 [95%CI: 1.12, 4.98]) and respite care needs (attended some college: adjusted OR: 2.47 [95%CI: 1.22, 4.98]; graduated college (adjusted OR: 2.47 [95%CI: 1.22, 4.98]). Caregivers who were not working were more likely to report support groups (adjusted OR: 2.22 [95%CI: 1.12, 4.43]) and respite care needs (adjusted OR: 2.19 [95%CI: 1.19, 4.03]). Caregivers caring for parents/parents-in-law (adjusted OR: 2.43 [95%CI: 1.10, 5.37]) or children (adjusted OR: 2.69 [95%CI: 1.17, 6.18]) vs. spouses/partners were more likely to report respite care needs. Caregivers at higher intensity were more likely to

report respite care needs, particularly those reporting high hours, both short-term (adjusted OR: 7.70 [95%CI: 3.43, 17.26]) and long-term (adjusted OR: 5.26 [95%CI: 2.15, 12.86]). Finally, those providing personal, hands-on care were more likely to report wanting classes about giving care (adjusted OR: 2.67 [95%CI: 1.07, 17.26]) and respite care needs (adjusted OR: 3.43 [95%CI: 1.43, 8.21]).

Discussion

Many U.S. rural caregivers report unmet support service needs, particularly those with higher caregiving intensity, Black caregivers, and those with higher educational attainment. There is wide variability in the types of support service needs for different types of caregivers, indicating a one-size-fits-all approach may not work in rural areas. Higher intensity caregiving is likely to necessitate more support,¹⁶ and rural caregivers may have more difficulty securing support services due to geographic barriers and financial constraints.³ Qualitative studies have documented unique challenges rural caregivers face in accessing critical support services, including caregiver training, mental health/counseling, and respite, often due to sheer lack of availability.¹⁷ The characteristics of unmet needs among rural caregiver is similar in countries other than the U.S., as reported in qualitative studies conducted in Australia¹⁸ and Canada.¹⁹ Since the onset of the COVID-19 pandemic, rural caregivers have reported a higher caregiver burden than urban caregivers,²⁰ and certainly, the pandemic has revealed critical infrastructure gaps in service provision to rural areas.

A notable finding from this study was the higher rates of unmet needs among Black rural caregivers, even controlling for socioeconomic factors: specifically classes about giving care, help with service access, and support groups. Multiple phenomena may contribute to Black caregivers reporting higher unmet needs, including worse overall healthcare access,²¹ higher minority discrimination and subsequent stress,²² and physical social isolation.²³ Healthcare disparities experienced by racially minoritized residents in rural areas are complex and may vary regionally and by topic. An evaluation of the U.S. National Family Caregiver Support Program found that non-White caregivers were more likely to report unmet support needs, although the same study also found lower unmet needs among rural vs. non-rural caregivers.²⁴ A study of U.S. Medical Expenditure Panel Survey data (2005-2010) found that Black rural dwellers had lower odds of two preventive health measures, cholesterol screening, and cervical

screening, than both Black urban dwellers and White rural dwellers.²⁵ A study using the U.S. National Social Life, Health, and Aging Project data (2010-2011) found that overall, rural vs. non-rural dwellers overall are less likely to report social

isolation, but the opposite was found for Black rural dwellers.²³ Thus, being minoritized in a rural area may contribute to further challenges in identifying and securing caregiver support services as with other healthcare services.

Table 2. Multivariable multinomial regression analysis predicting support needs overall and by type for rural caregivers, n = 6,189

	Any support service need vs. no need		Classes about giving care vs. no need		Help getting access to services vs. no need		Support groups vs. no need		Individual counseling vs. no need		Respite care vs. no need	
	adjusted OR*	95% CI	adjusted OR	95% CI	adjusted OR	95% CI	adjusted OR	95% CI	adjusted OR	95% CI	adjusted OR	95% CI
Gender												
Female	Ref		Ref		Ref		Ref		Ref		Ref	
Male	0.95	(0.71, 1.28)	2.55	(1.15, 5.69)	0.96	(0.64, 1.45)	0.95	(0.51, 1.80)	0.66	(0.34, 1.27)	0.57	(0.31, 1.07)
Age Group												
18-44	Ref		Ref		Ref		Ref		Ref		Ref	
45-64	1.18	(0.78, 1.79)	0.56	(0.19, 1.71)	1.34	(0.79, 2.28)	0.85	(0.36, 2.05)	1.5	(0.53, 4.24)	2.20	(0.86, 5.62)
65+	1.09	(0.66, 1.80)	1.07	(0.23, 4.95)	0.74	(0.41, 1.36)	1.02	(0.37, 2.81)	0.89	(0.22, 3.55)	6.30	(1.84, 21.63)
Race/ethnicity												
White, Non-Hispanic	Ref		Ref		Ref		Ref		Ref		Ref	
Black, Non-Hispanic	1.74	(1.17, 2.46)	5.13	(2.12, 12.45)	1.61	(1.03, 2.51)	2.31	(1.16, 4.60)	0.58	(0.21, 1.63)	1.21	(0.61, 2.37)
Other, including Hispanic	1.13	(0.70, 1.84)	2.76	(0.84, 9.06)	1.20	(0.68, 2.12)	0.52	(0.23, 1.19)	1.59	(0.57, 4.46)	0.35	(0.11, 1.17)
Educational attainment												
Graduated high school or less	Ref		Ref		Ref		Ref		Ref		Ref	
Attended some college or technical school	1.62	(1.19, 2.20)	1.11	(0.49, 2.52)	1.42	(0.93, 2.15)	1.72	(0.90, 3.28)	2.36	(1.12, 4.98)	2.47	(1.22, 4.98)
Graduate college, technical school, and beyond	1.85	(1.30, 2.48)	0.98	(0.32, 3.03)	1.53	(0.99, 2.37)	2.32	(1.17, 4.60)	2.03	(0.89, 4.62)	3.29	(1.57, 6.87)
Household income												
Less than \$15,000	Ref		Ref		Ref		Ref		Ref		Ref	
\$15,000 to less than \$25,000	1.28	(0.78, 2.11)	3.67	(0.73, 18.56)	0.74	(0.38, 1.44)	1.95	(0.78, 4.86)	2.42	(0.89, 6.57)	3.21	(1.23, 8.35)
\$25,000 to less than \$35,000	1.08	(0.63, 1.84)	1.99	(0.37, 10.65)	0.58	(0.29, 1.14)	3.11	(1.18, 8.24)	2.24	(0.67, 7.48)	0.93	(0.29, 2.98)
\$35,000 to less than \$50,000	0.94	(0.55, 1.62)	3.03	(0.47, 19.50)	0.60	(0.29, 1.22)	1.23	(0.45, 3.39)	0.89	(0.28, 2.82)	2.82	(0.88, 9.03)
\$50,000 or more	0.78	(0.45, 1.35)	2.61	(0.46, 14.64)	0.45	(0.22, 0.92)	1.65	(0.58, 4.71)	0.74	(0.25, 2.21)	1.92	(0.62, 5.94)
Don't know/Not sure/Missing	0.85	(0.48, 1.52)	4.63	(0.77, 27.79)	0.39	(0.20, 0.76)	1.77	(0.49, 6.44)	1.12	(0.37, 3.42)	2.52	(0.87, 7.29)
Employment Status												
Working	Ref		Ref		Ref		Ref		Ref		Ref	
Not working	1.29	(0.91, 1.83)	0.76	(0.31, 1.89)	0.95	(0.60, 1.52)	2.22	(1.12, 4.43)	1.57	(0.71, 3.45)	2.19	(1.19, 4.03)
Retired	0.84	(0.60, 1.16)	0.62	(0.22, 1.78)	0.95	(0.64, 1.43)	1.27	(0.64, 2.50)	0.49	(0.22, 1.09)	0.86	(0.36, 2.02)
Currently married or partnered												
Yes	Ref		Ref		Ref		Ref		Ref		Ref	
No	0.79	(0.58, 1.07)	0.56	(0.29, 1.12)	0.61	(0.40, 0.93)	1.24	(0.68, 2.25)	2.04	(1.09, 3.81)	0.48	(0.26, 0.88)
Children at home												
None	Ref		Ref		Ref		Ref		Ref		Ref	
At least one	0.95	(0.66, 1.36)	1.28	(0.42, 3.89)	0.96	(0.64, 1.46)	0.89	(0.43, 1.82)	0.67	(0.20, 2.19)	1.64	(0.80, 3.36)

Table 2. Multivariable multinomial regression analysis predicting support needs overall and by type for rural caregivers, n = 6,189

	Any support service need vs. no need		Classes about giving care vs. no need		Help getting access to services vs. no need		Support groups vs. no need		Individual counseling vs. no need		Respite care vs. no need	
	adjusted OR*	95% CI	adjusted OR	95% CI	adjusted OR	95% CI	adjusted OR	95% CI	adjusted OR	95% CI	adjusted OR	95% CI
Relationship to care recipient												
Spouse/ partner	Ref		Ref		Ref		Ref		Ref		Ref	
Parents/ parents-in-law	1.11	(0.76, 1.61)	0.51	(0.18, 1.42)	1.39	(0.84, 2.30)	1.41	(0.69, 2.90)	0.25	(0.09, 0.66)	2.43	(1.10, 5.37)
Child	1.39	(0.89, 2.17)	2.03	(0.59, 7.03)	1.27	(0.68, 2.37)	1.79	(0.84, 3.80)	0.38	(0.12, 1.24)	2.69	(1.17, 6.18)
Another relative	1.25	(0.81, 1.92)	0.63	(0.23, 1.71)	1.77	(0.97, 3.25)	1.24	(0.54, 2.87)	0.43	(0.16, 1.15)	0.65	(0.27, 1.57)
Friend or non-relative	0.67	(0.42, 1.08)	0.44	(0.11, 1.70)	0.81	(0.43, 1.50)	1.44	(0.58, 3.54)	0.08	(0.02, 0.28)	0.75	(0.21, 2.73)
Caregiving intensity												
Low hours, short duration	Ref		Ref		Ref		Ref		Ref		Ref	
High hours, short duration	2.19	(1.26, 3.79)	0.95	(0.33, 2.78)	1.52	(0.85, 2.74)	2.44	(0.93, 6.37)	1.23	(0.49, 3.09)	7.70	(3.43, 17.26)
High hours, long duration	1.80	(1.19, 2.73)	0.97	(0.20, 4.70)	1.30	(0.67, 2.54)	4.30	(1.25, 14.7)	3.63	(1.48, 8.88)	5.26	(2.15, 12.86)
Low hours, long duration	1.19	(0.84, 1.71)	1.22	(0.50, 2.94)	1.03	(0.63, 1.70)	1.71	(0.83, 3.52)	0.92	(0.43, 1.96)	3.24	(1.39, 7.53)
Caregiving, main health problem												
Dementia/Alzheimer's	Ref		Ref		Ref		Ref		Ref		Ref	
Cancer	0.75	(0.45, 1.28)	1.79	(0.39, 8.2)	0.70	(0.34, 1.44)	1.12	(0.37, 3.38)	0.53	(0.18, 1.54)	1.06	(0.31, 3.63)
Diabetes, cardiovascular disease, hypertension	0.64	(0.40, 1.01)	2.09	(0.64, 6.83)	0.81	(0.45, 1.46)	0.64	(0.26, 1.53)	0.22	(0.07, 0.66)	0.32	(0.13, 0.77)
Other reason	0.79	(0.53, 1.16)	0.68	(0.24, 1.93)	1.03	(0.61, 1.73)	1.37	(0.68, 2.75)	0.30	(0.14, 0.63)	0.71	(0.34, 1.46)
Provided personal care												
No	Ref		Ref		Ref		Ref		Ref		Ref	
Yes	1.40	(0.96, 2.02)	2.67	(1.07, 6.67)	1.12	(0.65, 1.91)	1.48	(0.72, 3.04)	1.25	(0.58, 2.69)	3.43	(1.43, 8.21)

*adjusted OR = Adjusted Odds Ratio. Models adjust for all listed covariates.

Other noteworthy findings were the lack of a strong association between income and unmet support service needs and the positive association between educational attainment and unmet needs.²⁶ These findings could suggest that caregivers across all income levels need to access informal support that may meet some caregivers' needs. One possible explanation for the educational association may stem from increased knowledge about the existence of support services, like respite, and the recognition of their potential utility. Unemployed caregivers were more likely to endorse a need for respite and support groups, suggesting a need for relief and/or the possibility that some caregivers would like to be employed but are unable to due to a lack of respite services. Finally, the finding that caregivers providing personal, hands-on care report wanting classes about giving care points toward a clear opportunity for service expansion in rural areas.

To further contextualize our findings, one qualitative study that interviewed U.S. Medicaid administrators, service agency managers and staff, and patient advocates across 14 states to investigate rural-urban disparities reported limited availability of long-term service and support providers, insufficient transportation, telecommunication barriers, and challenges to healthcare workforce and retention while also citing greater reliance on family caregivers, due to both cultural preferences and lack of home and community based service providers providers.²⁷ Together with the current study, these findings indicate some unique unmet needs of rural caregivers and possible targets for both intervention.

LIMITATIONS

Certain limitations of the data and design warrant consideration. The variability in access, availability,

and characteristics of caregiving services vary considerably across states and counties,²⁸ which may contribute to differences in caregiver experience, qualification for, and familiarity with possible services. The measures used in the BRFSS caregiving module may not adequately capture the nuance between formal home and community-based services, such as government- or community-funded services, which may be more impacted by policy, and services provided informally, such as through religious or social groups. Finally, the support service needs item was discontinued after 2018, limiting the ability to compare caregiver attitudes over time and since the COVID-19 pandemic. Capturing unmet support service needs in population-based services is critically important for informing all efforts to support caregivers, including national and state-level family support strategies. The BRFSS survey remains one of the only surveillance strategies for caregivers in the U.S. Nonetheless, the major strength of this study include the large size from a national representative sample, questions that allow for specific unmet support service needs, and the focus on a rural caregiver population.

Conclusion

In summary, many U.S. rural caregivers report unmet support service needs. In particular, caregivers of Black vs. White race, those with more educational attainment than a high school degree, and those engaged in higher vs. lower intensity caregiving. Future studies and public health plans to decrease rural-urban health disparities can benefit from targeting specific support services to subsets of rural caregivers with the highest unmet needs.

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