

Predictors of Psychological Distress Among Rural Family/Friend Caregivers of People Living With Dementia in the United States: Consequences of the COVID-19 Pandemic

Jasmine Santoyo-Olsson, DrPH, MS,^{1,2,*} Kenneth E. Covinsky, MD,^{2,3}

Catherine A. Chesla, RN, PhD,⁴ Kate Lorig, DrPH,⁵ Dolores Gallagher-Thompson, PhD, ABPP,⁶

Jing Cheng, PhD,⁷ Maritza Luzanilla, BA,¹ Elizabeth Macias Romo, MPH,¹

Giselle Aguayo Ramirez, BA,¹ Leah Karliner, MD, MAS,¹ and Veronica Yank, MD¹

¹Division of General Internal Medicine, University of California San Francisco, San Francisco, California, USA.

²Division of Geriatrics, University of California San Francisco, San Francisco, California, USA.

³San Francisco VA Healthcare System, San Francisco, California, USA.

⁴Family Health Care Nursing, University of California San Francisco, San Francisco, California, USA.

⁵Division of Immunology and Rheumatology, Stanford University, Palo Alto, California, USA.

⁶Psychiatry and Behavioral Sciences, Stanford University, Palo Alto, California, USA.

⁷Division of Oral Epidemiology and Dental Public Health, University of California San Francisco, San Francisco, California, USA.

*Address correspondence to: Jasmine Santoyo-Olsson, DrPH, MS. E-mail: jasmine.santoyo-olsson@ucsf.edu

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Abstract

Objectives: Caregivers of persons living with dementia in rural United States are a vulnerable population. During the coronavirus disease 2019 (COVID-19) pandemic, rural communities experienced heightened disparities in social services, healthcare, suicides, and mortality. Guided by the Caregiving Stress Process Model, this study examines the relationship between the stressors and resources of rural caregivers of persons living with dementia and their experience of depression, stress, and COVID-19.

Methods: One hundred and fifty-two rural caregivers of persons living with dementia completed an online survey, March 1, 2021–April 30, 2022. Analyses used baseline responses to validated scales and an open-ended question, “How has COVID impacted your life as a caregiver?” Dependent variables were depressive symptoms and stress. Bivariate and hierarchical linear regression analyses examined associations of stressors and resources with depressive symptoms and stress. Thematic analysis examined open-ended question responses.

Results: Among examined stressors, high care burden ($b = 1.94, p < .05$) and loneliness ($b = 0.76, p < .0001$) were positively associated with depressive symptoms. Loneliness ($b = 0.24, p < .05$) and ≥ 41 hr spent caregiving per week (reference 10–20 hr; $b = 0.99, p < .05$) were associated with stress. Among examined resources, self-efficacy for caregiving ($b = -0.21, p < .05$) was inversely associated with stress. Qualitative results confirmed quantitative results and identified additional pandemic-related themes in stressors and resources.

Discussion: We found that caregiver burden, loneliness, and caregiving hours were associated with greater psychological distress among rural caregivers of persons living with dementia during the pandemic, whereas self-efficacy for caregiving was protective. Rural caregivers need increased support to address care burdens and enhance psychological resources for caregiving.

Clinical Trial Registration Number: NCT04428112.

Keywords: Caregiver burden, Depression, Loneliness, Self-efficacy, Stress

Background

Family and friend caregivers of persons living with dementia in rural areas of the United States (henceforth “rural caregivers of persons living with dementia”) are a vulnerable population. Rural residents are often underresourced, have less medical coverage, and receive less recommended care than urban populations (Williams et al., 2023). Rural residents represent 19% of the U.S. population, and 80% are considered medically underserved (Williams et al., 2023). During the coronavirus disease 2019 (COVID-19) pandemic, rural communities experienced heightened disparities in social

services, healthcare (“2022 Alzheimer’s disease facts and figures,” 2022), suicide (Ehlman et al., 2022; Monteith et al., 2021), and all-cause mortality (Melotte, 2023). The pandemic created new stressors and additional burdens (Cohen et al., 2021; Greenberg et al., 2020) for rural caregivers of persons living with dementia.

Prior to the pandemic, rural caregivers of persons living with dementia depended on formal services already in short supply, such as respite care, support groups, or paid in-home services (“2022 Alzheimer’s disease facts and figures,” 2022). Rural caregivers felt the impacts of these shortages—reporting

higher rates of stress, depression, poor health, and financial distress from caregiving than urban counterparts (Ehrlich et al., 2015; Innes et al., 2011). When U.S. states mandated shelter-in-place during the early pandemic, community-based organizations had to decrease, suspend, or close their caregiver services (Brown et al., 2022; National Council on Aging, 2021). Service reductions left caregivers of persons living with dementia with fewer options for social connection or respite (Brown et al., 2022; National Council on Aging, 2021), placing them at greater risk for psychological distress and negative mental health outcomes.

There is a need to understand the mental health consequences of the pandemic for rural caregivers of persons living with dementia to protect their well-being and prepare for future pandemics or other rural societal disruptions (e.g., widespread rural hospital closures, massive wildfires; Johnson, 2023; Miller & Mossburg, 2022). Few articles have examined the impact of the pandemic among rural caregivers of persons living with dementia. These include a commentary (Williamson et al., 2020) calling for addressing the needs of rural caregivers of persons living with dementia during and beyond the pandemic, studies focusing on non-U.S. caregivers of persons living with dementia (L'Heureux et al., 2022), rural caregivers of persons living with dementia living in Virginia (Atkinson et al., 2022; Savla et al., 2021), and a U.S. rural-urban population-based sample of caregivers of persons with cognitive decline or other health conditions (Cohen et al., 2021). Emerging evidence shows that among a sample of Canadian rural caregivers of persons with a chronic illness, disability, or acute COVID infection, social loneliness and financial hardship were associated with caregiver anxiety (L'Heureux et al., 2022). Similar results were observed among rural caregivers of persons living with dementia living in Virginia, who also experienced decreased mental health and increased caregiving responsibilities (Atkinson et al., 2022; Savla et al., 2021). Similar increased caregiver burden results were observed among rural caregivers compared to their urban counterparts in a U.S. rural-urban population-based sample of caregivers of persons with cognitive decline or other health condition (Cohen et al., 2021). Although these studies provide some insight into the negative impact of the pandemic among rural caregivers, gaps in understanding both the negative and positive impact of the pandemic on U.S. rural caregivers of persons living with dementia remain (Williamson et al., 2020).

Conceptual Framework

This study is guided by the Caregiver Stress Process Model (Pearlin et al., 1990), which identifies sources of stress specific to caregiving. Measures of psychological distress—depressive symptoms, stress—are the study outcomes of interest because they are major foci of caregiving research (Pearlin et al., 1990; Schulz & Sherwood, 2008). Consistent with the Stress Process Model, this study examines characteristics of the caregiving context that may be associated with psychological distress (type of relationship between caregiver and person living with dementia, caregiver burden, loneliness; Pearlin et al., 1990; Schulz & Sherwood, 2008). Furthermore, the Stress Process Model posits that psychological resources (self-efficacy for caregiving, positive aspects of caregiving) and social resources (engagement in caregiving services) can be protective factors in relation to psychological distress (Pearlin et al., 1990; Schulz &

Sherwood, 2008; Zarit, 2012). Examining rural caregivers' experiences during the COVID-19 pandemic using the Stress Process Model is appropriate, because the model suggests that the effect of stressful life events on under-resourced groups should be explored separately from their effect on their more resource-rich counterparts. Caregivers living in rural areas experience greater stressors in the aftermath of the same life events as caregivers living in urban areas (Cohen et al., 2021).

The objective of this study is twofold: to (1) examine the extent to which caregiving stressors including caregiver burden, loneliness, social isolation, caregiving hours, everyday cognition of person living with dementia, COVID-19 limitations on caregiving, and psychological and support resources including self-efficacy for caregiving, positive aspects of caregiving, and engagement in caregiving services are associated with depressive symptoms and stress among rural caregivers of persons living with dementia; and (2) explore the pandemic-related contextual factors that influenced caregiver psychosocial experiences. The authors hypothesize that the indicated stressors are positively related to depressive symptoms and stress scores and the indicated resources are inversely related to depressive symptoms and stress scores.

Method

Parent Study

The study participants were recruited from the parent study, the Rural Dementia Caregiver Project (NCT04428112), a pragmatic hybrid randomized controlled trial and implementation evaluation of a 6-week skills-building online workshop designed to decrease depressive symptoms and stress among rural caregivers of persons living with dementia (Santoyo-Olsson et al., 2022). Caregivers were recruited in collaboration with rural-serving community organizations (Area Agencies on Aging, local nonprofit organizations) and other sources (radio, small local newspapers). Interested participants completed a screening survey online or by telephone. Inclusion criteria consisted of: being aged 18 years or older; self-identifying as living in a rural, farming, or small-town area of the United States; providing at least 10 hr of care a week to a family member or friend living with dementia; having internet access (low-speed included) on any device; having English proficiency; and reporting a stress level of 4 or more on a 10-point scale at time of screening (Lorig et al., 1996). Proof of clinical dementia diagnosis for the person living with dementia was not required. Eligible caregivers received an invitation email to join the study. Interested caregivers then completed the consent process and baseline survey online and were mailed \$20. The study is approved by the University of California San Francisco Institutional Review Board (approval #18-25814).

Current Study

This study is a cross-sectional secondary data analysis of data from the baseline survey of the parent study. The sample is composed of 152 caregivers who completed the survey between March 1, 2021 and April 30, 2022 (time frame of the second phase of the pandemic in the United States) during which Americans experienced alpha and delta COVID-19 variant surges and the first omicron variant surge. The end of the time frame was chosen because by May 2022 vaccinations were widely available (other than for infants and

preschoolers), cases had diminished, and the national travel mask mandate was discontinued.

Measures

We report internal consistency reliability for our sample for each measure below, as applicable.

Dependent measures

Two dependent variables were assessed. The Patient Health Questionnaire (PHQ-8) was used to assess depressive symptoms (Kroenke et al., 2009). The PHQ-8 is an 8-item scale and generates a score between 0 and 24. Higher scores indicate greater depressive symptoms (internal consistency reliability = 0.81). The single-item visual numeric stress scale was used to measure caregiver stress (Lorig et al., 1996). Respondents were asked, "Please select the box or the number that describes your stress in the past 2 weeks." The score ranges from 0 to 10, with higher score indicating higher stress.

Independent variables were stressors in the caregiving context and psychological and support resources.

Stressors in the caregiving context

Caregiver *burden* was assessed with the 12-item short form of the Zarit Burden Inventory (Bedard et al., 2001). Responses were summed, with scores ranging from 0 to 48 (internal consistency reliability = 0.89). Scores were categorized as no-to-moderate burden (score ≤ 20 ; reference group) and high burden (score > 20).

Caregiver *loneliness* was assessed using the 3-item University of California Los Angeles loneliness scale (Hughes et al., 2004). Respondents rated the extent to which they felt they lacked companionship, felt left out, and felt isolated from others. Responses were summed, with scores ranging from 3 to 9. Higher scores indicate greater loneliness (internal consistency reliability = 0.83).

Caregiver *social isolation* was assessed using the 6-item Lubben social isolation scale (Lubben et al., 2006). Respondents were asked three questions that evaluated family ties using the term "relatives": How many relatives do you see or hear from at least once a month? How many relatives do you feel close to such that you could call on them for help? How many relatives do you feel at ease with that you can talk about private matters? They are then asked the same three questions but with the term "friends" inserted in place of "relatives." A total score was the sum of the six items, with scores ranging from 0 to 30 (internal consistency reliability = 0.87). Scores were categorized as none (score ≥ 13 ; reference group) and social isolation (score < 12).

Caregiving hours were determined by asking respondents to "Enter your hours" as hours per week or per day. Hours reported by day were converted to hours per week. Hours were categorized as 10–20 (reference), 21–40, or ≥ 41 hr per week.

Everyday cognition of person living with dementia was assessed using the 12-item Everyday Cognition (ECog-12) measure (Tomaszewski Farias et al., 2011). Respondents rated the person living with dementia's everyday cognitive-relevant abilities, remembering current date, thinking ahead, and balancing checkbook. For each item, respondents compared the person living with dementia's current level of ability with how he or she functioned 10 years earlier. Ratings used the scale: 1 = better or no change compared to 10 years earlier, 2 = questionable/occasionally worse, 3 = consistently a little

worse, and 4 = consistently much worse. The ECog-12 score was created by averaging items. Scores ranged from 1 to 4. Higher scores indicate more cognitive impairments (internal consistency reliability = 0.91).

COVID-19 limitations on caregiving were measured using the 9-item Caregiver COVID-19 Limitations Scale (CCLS-9; Sheth et al., 2021). Respondents rated COVID-related difficulties, limitations, and changes including anxiety about contracting COVID-19, limitations on going out and having visitors, need for social isolation, changes in the person living with dementia's behavior, limitations in healthcare access, and economic changes. A CCLS-9 score was created by averaging items. Scores ranged from 1 to 10. Higher scores indicate more limitations (internal consistency reliability = 0.84).

Psychological and support resources

Caregiver self-efficacy was assessed using the 8-item Caregiver Self-Efficacy Scale (CSES-8; Ritter et al., 2020). Items assess caregiver's confidence in being able to obtain respite, control negative thoughts, stop worrying about future problems, cope with new situations, manage stress, perform self-care, find resources, and prevent disruptive behaviors. A CSES-8 score was created by averaging items. Scores ranged from 1 to 10. Higher scores indicate more self-efficacy (internal consistency reliability = 0.84).

Positive aspects of caregiving were assessed using a 9-item scale (Tarlow et al., 2004). Items assess caregiver perception of benefits of caregiving including feeling useful, feeling appreciated, and finding meaning. Responses were summed, with scores ranging from 9 to 45. Higher scores indicate greater positive aspects of caregiving (internal consistency reliability = 0.89).

Engagement in caregiving services was assessed by using a summary variable derived from 11 items that asked if the caregiver or persons living with dementia were currently using homemaker services, meal delivery services, transportation services, home health care services, nonmedical personal care services, adult day care, respite care, hospice services, support from a case manager/social worker, legal or financial services, or caregiver support groups/workshops (no or yes). Scores were the sum of "yes" responses (range = 0–11). Higher scores indicate more engagement. Scores were categorized as 0 (reference group), 1, 2–3, or 4 or more.

Covariates

Covariates included sociodemographic information. Respondents self-reported sociodemographic information (age [18–49, 50–64, ≥ 65]), sex (female, male, prefer not to answer), race (White, Black/African American, Latino/Hispanic, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander, mixed race, or other race), education (high school or less, technical school or associate's degree/some college, college graduate or higher), and U.S. state to classify their Census region of residence. Respondents also reported on persons living with dementia's relationship with them (parent, spouse, other relative, nonrelative), living arrangement (lives with caregiver, lives with someone else/lives in facility, lives alone), sociodemographic information (age [18–49, 50–64, ≥ 65]), sex (female, male, prefer not to answer), race (White, Black/African American, Latino/Hispanic, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander, mixed race, or other race), and dementia diagnosis (Alzheimer's disease, vascular dementia,

frontotemporal dementia, Lewy body dementia, other, don't know).

Open-ended question

At the time of the survey, there was a lack of literature on rural caregiver experiences during the pandemic. The open-ended survey question encouraged respondents to share details about their experiences, including pandemic-related experiences that the research team could not anticipate (Rouder et al., 2021) and would not know to capture using validated, quantitative instruments. The open-ended question stated, "We know that things are difficult for many people now because of COVID. How has COVID impacted your life as a caregiver?" There was no word limit to respondent responses (i.e., could leave blank, or write as many sentences as desired).

Analyses

Quantitative and qualitative analyses were conducted separately. Results were compared and combined at the stage of interpretation of results.

Quantitative analyses

Between March 1, 2021 and April 30, 2022, 152 participants completed the baseline survey and were used in this secondary analysis. Descriptive statistics were used to summarize the sample. Psychometric properties (internal consistency reliabilities) were examined in this sample and are listed in the *Measures* section above. Simple linear regressions examined bivariate associations of independent and dependent variables. Because of the large number of independent variables, data analyses were conducted in a multiple-step approach. Only covariate variables that were significantly associated with depressive symptoms or stress at $p < .2$ in bivariate analyses or supported by the literature were included. Caregiver age, sex, race/ethnicity, education, Census region (based on state of residence), and relationship to person living with dementia were examined as covariates. Hierarchical regression analysis was conducted to determine the association of the variables of interest with depressive symptoms and stress separately, as follows: model 1, covariates only; model 2, stressors in the caregiving context were added to model 1; and model 3, psychological and support resources were added to model 2. Prior to multivariable analyses, independent variables were examined for multicollinearity using the Tolerance and Variance Inflation Factor (VIF). Multicollinearity was defined as a VIF higher than 5 or tolerance lower than 0.1. If multicollinearity was identified, then one of the correlated independent variables would be dropped from the model. We report unstandardized regression parameter estimates (b) and standard errors, where b indicates the change in the dependent variables per each unit change in an independent variable. Model fit was evaluated using a two-tailed test with a $p < .05$ level of significance, and by examining residuals and R^2 . Analyses were performed on SAS, version 9.4.

Qualitative analyses

The qualitative analysis process involved three reviewers trained in qualitative research (J. Santoyo-Olsson, E. Macias Romo, and V. Yank). Thematic analysis (Braun & Clarke, 2006) was applied to responses to the open-ended survey question. Coders read responses line-by-line and identified codes. Codes were organized into a team codebook that

guided second-pass coding. Codes were applied independently to each response by two coders. Coding discrepancies were resolved through discussion among the coding team to reach consensus. The coding team iteratively discussed the codes to organize them into major themes and subthemes and selected exemplar quotes to illustrate the themes. Coding and organization of codes were facilitated by Excel software.

Results

Quantitative Results

Participants' mean age was 60.4 (standard deviation [SD] = 12.1; Table 1). The majority were female (82%) and self-identified as White (86%). Over half (55%) had completed a college degree or higher. Participants represented 33 states and all Census regions: 34% lived in the West, 31% in the Midwest, 18% in the South, and 17% in the Northeast. Most participants provided caregiving to a parent (44%) or spouse (41%).

The majority (76%) of persons living with dementia lived with their caregiver, were aged 65 years or older (80%), were female (57%), and identified as White (88%; Table 2). Dementia diagnosis varied: 30% had Alzheimer's disease, 12% vascular dementia, 11% frontotemporal dementia, 10% Lewy body dementia, 7% other, and caregivers of 31% did not know the dementia type.

Caregivers had a mean PHQ-8 score for depressive symptoms of 5.5 ($SD = 3.9$, observed range 0–18) and mean score for stress of 6.6 ($SD = 1.8$, observed range 1–10; Table 1). They also had a mean *loneliness* score of 5.9 ($SD = 1.9$, observed range 3–9); mean persons living with dementia's everyday cognition score of 3.3 ($SD = .7$, observed range 1.63–4), and mean COVID-19 limitations on caregiving score of 4.4 ($SD = 2.0$, observed range 1–9.4). Caregivers had a mean self-efficacy for caregiving score of 5.2 ($SD = 1.8$, observed range 1.13–9.5) and mean positive aspects of caregiving score of 30.1 ($SD = 7.9$, observed range 9–45). Over half (64%) reported high care burden. More than a third (39%) reported social isolation. Almost half (49%) performed 41 or more hours of caregiving per week. About a third (32%) engaged in 2–3 caregiving services and 32% engaged in 4 or more services.

Bivariate analysis

Neither depressive symptoms nor stress were associated with caregiver's age, sex, race/ethnicity, education, region, and caregiver relationship to person living with dementia at $p < .2$ in the bivariate analysis, but were included in models based on existing literature. The correlation between depressive symptoms and stress was 0.42 ($p < .0001$).

Depressive symptoms models

There was no presence of multicollinearity between independent variables (VIF: 1.11–1.77, tolerance 0.56–0.90) in the depressive symptoms model; thus, all independent variables were included. When a model was run using sociodemographic variables alone, none of the covariates were associated with depressive symptoms (Supplementary Table 1). Table 3 presents results of the depressive symptoms models. In model 1, stressors in the caregiving context explained 35% of the variance in depressive symptoms ($R^2 = 0.347$; $F(22, 127) = 3.07$, $p < .0001$). Compared to caregivers of persons living with dementia reporting none-to-moderate burden, caregivers

Table 1. Demographic Characteristics of Rural Caregivers of Persons Living With Dementia, March 1, 2021–April 30, 2022 (*N* = 152)

Characteristic	<i>n</i> (%)	Mean (<i>SD</i>)
<i>Caregiver characteristics</i>		
Age		
18–49	29 (19.1)	
50–64	64 (42.1)	
≥65	59 (38.8)	
Sex		
Female	124 (81.6)	
Male	26 (17.1)	
Prefer not to answer	2 (1.3)	
Race/ethnicity		
White	130 (85.5)	
Black/African American	10 (6.6)	
Latino/Hispanic	3 (2.0)	
American Indian/Alaska Native	4 (2.6)	
Other ^a	5 (3.2)	
Education		
High school or less	13 (8.6)	
Technical school or associate’s degree/ some college	55 (36.2)	
College graduate or higher	84 (55.3)	
U.S. census region		
West	52 (34.2)	
Midwest	47 (30.9)	
South	28 (18.4)	
Northeast	25 (16.5)	
Caregiver relationship to person living with dementia		
Parent	67 (44.1)	
Spouse	62 (40.8)	
Other relative	16 (10.5)	
Nonrelative	7 (4.6)	
<i>Caregiver outcome measures</i>		
Depressive symptoms (possible range 0–24, higher = more depression symptoms)		5.49 (3.89)
Stress (possible range 1–10, higher = worse)		6.59 (1.82)
<i>Stressors in the caregiving context</i>		
Care burden		
None to moderate (0–20)	55 (36.2)	
High (>20)	97 (63.8)	
Loneliness (possible range 3–9, higher = worse)		5.88 (1.89)
Social isolation		
No	93 (61.2)	
Yes	59 (38.8)	
Hours spent caregiving per week ^b		
10–20	38 (25.0)	
21–40	39 (25.7)	
≥41	75 (49.3)	
Person living with dementia’s everyday cognition (possible range 1–4, higher = more cognition limitations)		3.29 (0.68)

Table 1. Continued

Characteristic	<i>n</i> (%)	Mean (<i>SD</i>)
COVID-19 limitations on caregiving (possible range 1–10, higher = more limitations)		4.44 (2.03)
<i>Protective factors and resources</i>		
Self-efficacy for caregiving (possible range 1–10, higher = more self-efficacy)		5.20 (1.84)
Positive aspects of caregiving (possible range 9–45, higher = more positive aspects)		30.14 (7.89)
Engagement with caregiving services		
0 services	24 (15.8)	
1 service	32 (21.1)	
2–3 services	48 (31.6)	
4 or more services	48 (31.6)	

^aThe “other” category consists of Native Hawaiian/Other Pacific Islander (*n* = 1), mixed race/ethnicity (*n* = 1), and other race/ethnicity (*n* = 3).
^bEligibility criteria for the parent study required at least 10 hr of caregiving per week.

reporting high care burden reported higher levels of depressive symptoms ($b = 2.44, SE = 0.71; p < .001$). Loneliness also was positively associated with depressive symptoms ($b = 0.80, SE = 0.18; p < .0001$). In model 2, adding psychological and support resources explained 39% of the variance in depressive symptoms ($R^2 = 0.388; F(27, 122) = 2.87, p < .0001$). High care burden ($b = 1.94, SE = 0.80; p < .05$) and loneliness ($b = 0.76, SE = 0.18; p < .0001$) remained positively associated with depressive symptoms. Psychological and support resources were not associated with depressive symptoms.

Stress models

There was no presence of multicollinearity between independent variables in the stress model (VIF: 1.11–1.77, tolerance: 0.56–0.90); thus, all variables were included. When the model was run using sociodemographic variables alone, none of the covariates were associated with stress score (Supplementary Table 1). Table 3 presents the results of the stress models. In model 1, stressors in the caregiving context explained 25% of the variance in stress ($R^2 = 0.251; F(22, 127) = 1.94, p < .05$). Compared to caregivers reporting none-to-moderate burden, caregivers reporting high care burden reported higher levels of stress ($b = 0.86, SE = 0.36; p < .05$). Loneliness also was positively associated with stress ($b = 0.25, SE = 0.09; p < .01$). In model 2, adding psychological and support resources explained 30% of the variance in stress ($R^2 = 0.298; F(27, 122) = 1.92, p < .01$). Loneliness remained positively associated with stress ($b = 0.24, SE = 0.09; p < .05$). Compared to caregivers of persons living with dementia reporting 10–20 hr spent caregiving per week, caregivers reporting ≥41 hr spent caregiving per week reported higher levels of stress ($b = 0.99, SE = 0.41; p < .05$). In contrast, self-efficacy for caregiving was inversely associated with stress ($b = -0.21, SE = 0.10; p < .05$).

Qualitative Results

All 152 participants provided a response to the open-ended question. Twenty-five gave single-word responses that could not be coded (e.g., “yes,” “greatly”); the 127 remaining responses were analyzed. Responses had a mean sentence

Table 2. Demographic Characteristics of Persons Living With Dementia, March 1, 2021–April 30, 2022 ($N = 152$)

Characteristic	n (%)
Living arrangement	
Lives with caregiver	116 (76.3)
Lives with someone else/lives facility	24 (15.8)
Lives alone	12 (7.9)
Age	
18–49	7 (4.6)
50–64	23 (15.1)
≥ 65	121 (79.6)
Missing	1 (0.7)
Sex	
Female	86 (56.6)
Male	65 (42.8)
Prefer not to answer	1 (0.7)
Race/ethnicity	
White	134 (88.2)
Black/African American	8 (5.3)
Latino/Hispanic	4 (2.6)
American Indian/Alaska Native	2 (1.3)
Other ^a	3 (2.0)
Missing	1 (0.7)
Dementia diagnosis	
Alzheimer's disease	46 (30.3)
Vascular dementia	18 (11.8)
Frontotemporal dementia	16 (10.5)
Lewy body dementia ^b	15 (9.9)
Other ^c	10 (6.6)
Don't know	47 (30.9)

^aThe "other" category consists of Native Hawaiian/Other Pacific Islander ($n = 1$) and mixed race/ethnicity ($n = 2$).

^bLewy body dementia includes both dementia with Lewy bodies and Parkinson disease with dementia.

^cTraumatic brain injury-related dementia, neurodegeneration/dementia not otherwise specified.

count of 1.85 ($SD = 1.32$, observed range 1–10) and mean word count of 23.15 ($SD = 24.46$, observed range 2–189). Seven themes were identified on pandemic-related psychosocial contextual factors (Table 4). Six themes identified negative impacts, and one theme identified positive impacts. Caregivers described challenges of *additional care responsibilities* that were dementia- and nondementia-related and how it put a strain on their well-being. New responsibilities included performing dementia caregiving tasks previously performed by others and supervising children no longer able to go to school or daycare. Caregivers highlighted experiences of *decreased social interactions* such as inability to visit family and friends or go to restaurants, social clubs, house of worship, or sporting and community events. In a related theme, caregivers highlighted their *negative feelings of isolation and loneliness*.

I have felt isolated, alone, lonely. I have moments I feel stuck! ID 1347

Fourth, caregivers experienced *increased worry and anxiety*, particularly about COVID-19 harming their person living with dementia. Caregivers also worried that they would

leave their person living with dementia unsupported if they became infected themselves. In a few cases, caregivers delayed accessing needed services, including medical care or home repair services, due to fear of COVID-19 exposure. Fifth, caregivers identified multiple *challenges of the pandemic related to public health and formal services* (with three subthemes). Subthemes included difficulty following public health guidelines persons living with dementia did not understand (e.g., need for masking), reduced contact and support for persons living with dementia who were living in facilities (e.g., nursing homes), and inability to access formal services that previously supported them (e.g., support groups) or persons living with dementia (e.g., adult daycare). Sixth, caregivers described a *decline in persons living with dementia health* that they attributed to pandemic-related psychosocial factors (e.g., loss of social contact, usual activities). Caregivers noted that persons living with dementia became more agitated or more dependent on them.

She has gone downhill due to the social isolation and she is much worse in terms of memory decline, irritability, and physical strength. ID 947

Finally, caregivers highlighted unexpected *positive impacts of the pandemic on their psychosocial context*, with three subthemes. They identified the benefits of having increased time with their person living with dementia.

Covid allowed for greater focus on just my wife. ID 1344

Caregivers engaged in new uses of technology (e.g., Zoom) to access joyful activities, reconnect with friends and family, and attend online church services or support groups. Lastly, caregivers noted that the pandemic prompted noncaregivers to better understand their caregiving context, including isolation predating the pandemic, because COVID-19 forced everyone into a similar state.

Discussion

Applying the Caregiving Stress Process Model, this study assessed associations between stressors and psychological and support resources in the caregiving context and depressive symptoms and stress among U.S. rural caregivers of persons living with dementia during the COVID-19 pandemic, as well as contextualizing factors. Only two stressors in the caregiving context (care burden and loneliness) were positively associated with depressive symptoms. Social isolation, hours spent caregiving per week, everyday cognition of persons living with dementia, COVID-19 limitations on caregiving, and psychological and support resources were not associated with depressive symptoms. Two stressors in the caregiving context (loneliness and hours spent caregiving per week) were positively associated with stress. One of the psychological and support resources (self-efficacy for caregiving) was inversely associated with stress. High care burden, social isolation, everyday cognition of persons living with dementia, and COVID-19 limitations on caregiving and two of the psychological and support resources (positive aspects of caregiving, engagement in caregiving services) were not associated with stress. In qualitative results, caregivers characterized negative impacts of the pandemic but also identified

Table 3. Association of Stressors in the Caregiving Context and Protective Factors and Resources With Depressive Symptoms and Stress, March 1, 2021–April 30, 2022 ($N = 152$)

Variable	Depressive symptoms				Stress			
	Model 1 ^{a,b}		Model 2 ^{a,c}		Model 1 ^{a,d}		Model 2 ^c	
	<i>b</i>	<i>SE</i>	<i>b</i>	<i>SE</i>	<i>b</i>	<i>SE</i>	<i>b</i>	<i>SE</i>
<i>Stressors</i>								
High care burden (ref. none to moderate)	2.44***	0.71	1.94*	0.80	0.86*	0.36	0.33	0.41
Loneliness	0.80****	0.18	0.76****	0.18	0.25**	0.09	0.24*	0.09
Social isolation (ref. none)	-0.29	0.64	-0.57	0.66	-0.01	0.32	-0.18	0.33
Hours spent caregiving per week								
21–40 (ref. 10–20)	-1.14	0.83	-0.67	0.85	0.18	0.42	0.40	0.43
≥41 (ref. 10–20)	-0.67	0.80	-0.39	0.82	0.75	0.40	0.99*	0.41
Person living with dementia's everyday cognition	-0.34	0.43	-0.42	0.44	0.07	0.22	0.06	0.22
COVID-19 limitations on caregiving	-0.05	0.16	-0.06	0.16	-0.08	0.08	-0.11	0.08
<i>Psychological and support resources</i>								
Self-efficacy for caregiving			-0.26	0.20			-0.21*	0.10
Positive aspects of caregiving			-0.04	0.04			-0.03	0.02
Engagement in caregiving services								
One (ref. none)			-0.25	0.96			-0.32	0.49
2–3 (ref. none)			1.23	0.92			-0.35	0.47
4 or more (ref. none)			0.04	0.94			0.05	0.48

Notes: ref = reference; *SE* = standard error.

^aAdjusting for the following covariates: caregiver's age, sex, race/ethnicity, education, region, and caregiver's relationship to person living with dementia.

^b $R^2 = 0.347$; $F(22, 127) = 3.07$, $p < .0001$.

^c $R^2 = 0.388$; $F(27, 122) = 2.87$, $p < .0001$.

^d $R^2 = 0.251$; $F(22, 127) = 1.94$, $p < .05$.

^e $R^2 = 0.298$; $F(27, 122) = 1.92$, $p < .01$.

* $p < .05$. ** $p < .01$. *** $p < .001$. **** $p < .0001$.

ameliorating factors. These findings point to the importance of assessing stressors and resources that influence the psychosocial distress of rural caregivers of persons living with dementia during major social disruptions or disasters, such as the resolved COVID-19 pandemic, ongoing mass closures of U.S. rural hospitals (Cecil G. Sheps Center for Health Services Research, 2023; Johnson, 2023), and catastrophic wildfires (Miller & Mossburg, 2022; Spencer, 2023).

The results from this study were compared to other studies to determine unique versus similar findings. First, this study found that care burden was associated with greater psychosocial distress, as measured by higher levels of caregiver depressive symptoms. The findings are consistent with a qualitative study of rural caregivers of persons living with dementia in Virginia that identified additional responsibilities were associated with stress (Atkinson et al., 2022) and a survey of rural–urban caregivers of persons with a disability, cognitive decline, or other health condition that found that rural caregivers reported greater increases in care burden than urban caregivers (Cohen et al., 2021). In this study, qualitative themes help explain prior findings by conveying the many additional care responsibilities respondents faced, such as addressing all of their persons living with dementia's physical and emotional needs in the absence of usual support services.

Second, this study found that increased loneliness was associated with greater levels of depressive symptom and stress. An online international convenience sample of 2,287 English-speaking caregivers of persons with any chronic illness or disability reported a similar finding of increased loneliness

scores during the pandemic (Grycuk et al., 2022). Caregiver comments in the current study generated two themes on difficult feelings/emotions that reinforce the quantitative findings. One theme captured feelings of isolation and loneliness due to lack of interpersonal contact. A second theme acknowledged increased worry and anxiety related to COVID (e.g., being unable to perform their caregiving role if they became infected). These findings are similar to qualitative findings from a study in rural Virginia in which caregivers felt an increased need for vigilance to keep their person living with dementia safe (Atkinson et al., 2022).

Participants also commented in detail about decreased social interactions, including diminished contact with families, friends, and other community members whose company they and their person living with dementia enjoyed before the pandemic. In a related theme, they described how their person living with dementia's loss of social interaction caused a notable decline in persons living with dementia health. Their insight into this connection parallels findings in the biological and psychological literature that prolonged isolation is detrimental to health (Donovan & Blazer, 2020). The findings are consistent with findings from two online surveys—the Grycuk et al. survey and a survey of 126 Canadian rural caregivers of persons with a chronic illness, disability, or acute COVID-19 infection that also documented a lack of opportunities to socialize (Grycuk et al., 2022; L'Heureux et al., 2022). In contrast, a study of 26 caregivers of older adults reported maintaining a moderate level of socializing (Marziliano et al., 2022). Despite the qualitative findings on social isolation, this study did not identify an association between the quantitative

Table 4. Themes and Subthemes of Caregiver Responses—How COVID-19 Pandemic affected Their Life As a Caregiver

Theme and subtheme	Illustrative quotes
Additional care responsibilities	“I’ve had to work through the pandemic and have had COVID twice but had to continue working. Had to care for children impacted by school closures due to COVID.” ID 1288 “I am totally caring for my mom 100% of the time unless she’s sleeping.” ID 918
Decreased social interactions	“Limited outside socializing, limited getting together with close friends and family.” ID 1338 “It has limited the things/places I can take my sister. We use to go to the movies, bowling, crafts, etc. Covid has impacted those activities.” ID 923
Negative feelings of isolation and loneliness	“I am distressed about not being together with family and friends.” ID 1155
Increased worry and anxiety	“More worry about my husband getting COVID. Also, if I got COVID, how would he manage?” ID 1029
Challenges of the pandemic related to public health and formal services	
• Difficulty following public health guidelines	“My husband does not understand what the virus is, or consequences of not masking or socially distancing. Getting him to mask has been extremely difficult and frustrating for me.” ID 990 “Doctor’s appointments more stressful due to trying to get Ma to keep her mask on. Sitting in vehicle waiting to be called in prior to appointment difficult.” ID 1383
• Reduced contact or support for persons living with dementia in facilities	“I was not able to get into my mom’s assisted living to do all the organizing of supplies, paperwork, meds, etc. As a result, it is a mess and I am now unraveling and getting it straightened out.” ID 947
• Inability to access formal services	“Tougher. I work full-time and sometimes have to care for my mother during those hours because there is no outside day care I was able to depend on. Very hard.” ID 1391
Decline in health of persons living with dementia from loss of social interaction	“My mother-in-law has deteriorated significantly since the start of the pandemic due to lack of social interaction and participation in activities.” ID 1258
Positive impacts of the pandemic on caregiver psychosocial context	
• Increased time with persons living with dementia	“I now work remotely due to COVID and to be available for my parents.” ID 1478
• New use of technology for joyful activities	“The only positive is that I’ve reconnected with friends in another state via weekly Zoom calls.” ID 913
• Better understanding by noncaregivers	“I was isolated because of her disease and behavior; covid isolation was no change. In fact, it was helpful because other people had to live the isolated life I do.” ID 189

measure of caregiver social isolation and either depression or stress on hierarchical analyses.

A possible explanation for these seemingly disparate findings is the small sample size of the current study. Another possible explanation relates to the scale that was used, the Lubben social isolation scale (Lubben et al., 2006), and the timing of scale administration during the COVID-19 pandemic. The Lubben social isolation scale is designed to objectively quantify social network size and contact, rather than subjective feelings or psychological experiences. This study occurred during the second phase of the pandemic (March 1, 2021 to April 30, 2022) in the U.S. and by this time, some caregivers may have psychologically adjusted to restricted contact with relatives and friends, which is what the Lubben scale assesses (Lubben et al., 2006). Furthermore, some caregivers may have “reframed” this social restriction as a positive, protective action they were taking (possibly associated with positive feelings) to minimize the risk of COVID-19 infections for themselves and their persons living with dementia.

The COVID-19 limitations on caregiving (CCLS-9) were not associated with depression or stress. Sheth et al. (2021) administered the scale to caregivers of children and adults early in the pandemic (April 2020–June 2020) and found that higher scores were associated with increased stress. By the time frame of this study, caregivers may have adjusted, at least in part, to some of the COVID-related limitations on

caregiving measured by the CCLS-9 (e.g., economic impacts, limitations in access to healthcare). The authors have not found other published studies that used the CCLS-9. Although the quantitative results were not significant, the qualitative results provide insight into how COVID increased caregiving challenges related to public health and formal services (e.g., difficulty having persons living with dementia understand mask mandates, inability to access usual services). In related findings, aging service organizations documented a reduction or termination of respite care, adult daycare, and other services during the pandemic (Brown et al., 2022; National Council on Aging, 2021). Because rural communities experienced heightened disparities in social and health services during the pandemic (“2022 Alzheimer’s disease facts and figures,” 2022), it is likely that rural caregivers of persons living with dementia suffered disproportionate limitations in aging services.

Despite facing many challenges, caregivers in this study identified psychological resources during COVID. This study found that self-efficacy for caregiving scores were inversely associated with stress. In qualitative findings, respondents reported positive impacts of COVID on their psychosocial context—including appreciation of increased time with persons living with dementia, benefits of learning to use technology in new ways to connect to others, and relief from having others newly understand the isolation of caregiving that

might expand their empathy for caregivers. Results parallel findings from a systemic review of prepandemic, primarily quantitative studies that many caregivers experience positive impacts of caregiving (Wang et al., 2022). During the early pandemic, an interview study of 26 Australian caregivers of persons living with dementia identified themes of improved relationships with persons living with dementia/family and other positive aspects of pandemic caregiving (Tulloch et al., 2022). Finally, a qualitative study of 10 caregivers of persons living with dementia similarly reported that caregivers found some comfort from the pandemic imposing their caregiving reality on everyone (O'Connor et al., 2023).

Limitations

The data in this study are cross-sectional from the baseline survey of the parent study. Participants needed to be willing and able to enter an online workshop to enroll in the parent study. Although the study required internet access, access could be low-speed or high-speed on any device, and in the time frame of the study, 80% of rural Americans reported using the internet at least daily (Vogels, 2021). The time frame for this analysis is the second phase of the U.S. pandemic (March 1, 2021 and April 30, 2022); whether observed associations persist beyond this time frame is unknown. Yet findings may have implications for societal disruptions or disasters that place vulnerable and underresourced rural caregivers of persons living with dementia under a greater degree of stress. This study did not include caregivers from all 50 U.S. states, but participants were residents of 33 states representing all Census regions. The study sample consisted primarily of caregivers who self-identified as White and had a college degree. For context, among rural Americans of similar age range to the study sample, 78% identify as White versus 86% in this sample (Housing Assistance Council, 2012), and 21% have earned a college degree or higher versus 55% in this sample (Postsecondary National Policy Institute, 2023). This study also was limited to a small sample size of caregivers with English proficiency. Larger and more diverse samples, with targeting of caregiver groups commonly underrepresented in research and with surveys available in Spanish and other languages, are required to understand the needs and concerns of rural caregivers of persons living with dementia more fully. Furthermore, in this study, qualitative data collection consisted of one open-ended survey question. However, rural caregivers of persons living with dementia are an understudied population, and this study is a first step in understanding the psychological distress of rural caregivers of persons living with dementia during COVID-19 (Williamson et al., 2020) and insights may inform efforts to address their psychological distress during current or future periods of rural societal disruption, such as the ongoing, widespread closures of rural hospitals (Cecil G. Sheps Center for Health Services Research, 2023; Johnson, 2023) or massive wildfires in the Western U.S. and Hawaii (Miller & Mossburg, 2022; Spencer, 2023).

Conclusions

Rural caregivers of persons living with dementia are a vulnerable and underserved population. This study found that care burden, loneliness, hours spent caregiving, and self-efficacy for caregiving influenced the psychological distress of rural caregivers during the COVID-19 pandemic. It also revealed themes on their complex psychosocial context that can help

shape future interventions to address their distress. Rural caregivers of persons living with dementia need increased services that promote caregiving self-efficacy and reduce psychosocial stressors endured or exacerbated during COVID-19 to better support them during the postpandemic period and future catastrophic events.

Supplementary Material

Supplementary data are available at *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* online.

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Conflict of Interest

All but one author declares no conflicts of interest. K. Lorig is a partner in the Self-Management Resource Center (offers licensing and training for Building Better Caregivers workshop) and receives royalties from Bull Publisher for books used in workshops.

Data Availability

The data that support the findings of this study are available from the corresponding author, J. Santoyo-Olsson, upon reasonable request.

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