

## Special Article

# Dementia Caregiving During the “Stay-at-Home” Phase of COVID-19 Pandemic

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## Abstract

**Objective:** The objective of this study was to assess family caregivers' primary appraisal of stressors related to COVID-19 stay-at-home orders, secondary appraisal of resources and support availability, and use of coping strategies as predictors of perceived role overload during the stay-at-home phase of the pandemic.

**Method:** Telephone interviews with 53 family caregivers of persons with dementia from rural Virginia 2 weeks after enactment of the governor's stay-at-home order using structured and open-ended questions were conducted.

**Results:** Caregivers who were more concerned about the COVID-19 pandemic were at greater odds of experiencing high role overload than those who recognized positive aspects of the pandemic, as were those who received insufficient support from family and friends.

**Discussion:** Use of the transactional model of stress responses yielded important insights about families coping with dementia. Caregivers' perceptions of the pandemic's impact varied, with differential effects on their well-being.

**Keywords:** Family caregivers, Memory loss, Rural, Stress

Although dementia does not increase the risk of COVID-19, dementia-related behaviors and underlying comorbidities render persons with dementia (PwD) vulnerable to the virus. Family caregivers (CGs) assist PwD in completing everyday activities requiring memory and judgment (personal hygiene, medications, safety), often relying on home- and community-based services to augment their caregiving. While stay-at-home orders slowed the spread of COVID-19, restrictions reduced availability of formal services, which could result in PwD's needs being unmet or undermet. As relatives and friends practiced social distancing and businesses reduced non-essential services, CGs and PwD may

experience feelings of loneliness and isolation. This may be particularly true for families with little telecommunication knowledge or access and those in rural communities whose socializing depends on in-person support and community events.

Under typical circumstances, CGs of PwD report high burden and distress (Riffin et al., 2017). During the pandemic, CGs are providing continuous care with little or no assistance from other family members or care services, likely increasing distress. Although news media have reported increases in psychological crises and family violence (Kelland, 2020), how CGs are coping with providing continuous care

to their PwD with minimal respite has not been studied. Invoking Lazarus and Folkman's (1984) transactional theory of stress (Figure 1), our aim was to examine CGs' primary appraisal of pandemic-related stressors, secondary appraisal of resources and support availability, and use of coping strategies as predictors of their adjustment to caregiving (perceived role overload) during the stay-at-home phase of the pandemic. The research questions were:

1. How was the stay-at-home phase of the COVID-19 pandemic appraised by CGs of PwD living in rural Virginia?
2. Did the stay-at-home phase affect the availability and use of home- and community-based services and informal support?
3. How did appraisal of the pandemic, availability of services, support from family and friends, and personal coping influence caregiving stress (role overload)?

## Method

### Sample and Procedure

This study originated with 123 family CGs of PwD, aged 30–82 years, recruited through Carilion Clinic, Area Agencies on Aging, and community advertising. Participants lived in rural Southwest Virginia for 47 years on average. At the end of the original study, 117 CGs gave permission to be re-contacted. Approximately 2 weeks after the stay-at-home order was announced (March 30, 2020), CGs were contacted about the

current study. Thirty PwD had died (51%), 20 CGs were unreachable via telephone (34%), 6 CGs were not interested in participating (10%), and 3 CGs declined because of their poor health (5%). Of the 58 CGs that agreed to participate, 5 CGs were supporting PwD living in a residential facility. Thus, for the current analysis, the sample included 53 CGs of PwD living at home. After confirming consent, CGs participated in a 30-min telephone interview comprising survey items and open-ended questions. Interviews were conducted between April 14 and May 1, were audio-taped, and were transcribed verbatim. The first author coded responses to open-ended questions using theoretical constructs from the transactional model of stress; the second author recoded 20% of the interviews to ensure coding accuracy ( $\kappa = 0.90$ ). Participants were not asked to affirm coding of their responses.

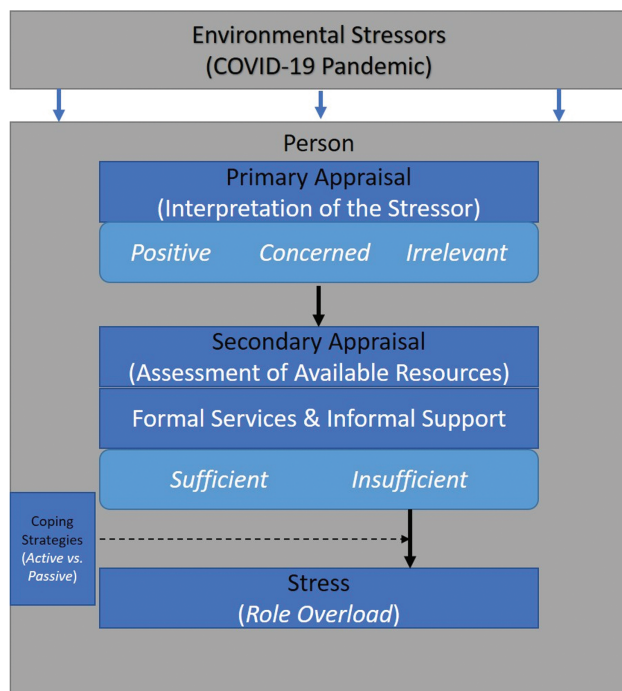
## Measures

Structured survey items provided PwD's living arrangement and CGs' relationship with PwD, age, perception of

**Table 1.** Participant Characteristics (N = 53)

Characteristic	M (SD) or N (%)
<b>Living arrangement of PwD</b>	
Live alone	12 (22.64)
Lives with someone else	5 (9.43)
Lives with CG	36 (67.92)
<b>CG relationship with PwD</b>	
Spouse or partner	22 (41.51)
Adult child	26 (49.06)
Sibling	2 (3.77)
Niece or grandchild	3 (5.66)
CG age in years	64.23 (11.06)
<b>CG ability to get along on income</b>	
Can't make ends meet	1 (1.89)
Have just enough; never left over	12 (22.64)
Have enough with a little left over sometimes	25 (47.17)
Always have money left over	15 (28.30)
<b>CG race and ethnicity</b>	
White	45 (84.91)
African American	8 (15.09)
Hispanic or Latino/a	1 (1.89)
<b>CG primary appraisal of stressors related to COVID-19</b>	
Positive (beneficial, constructive, sanguine)	6 (11.30)
Irrelevant (indifferent)	14 (26.40)
Concerned (taking precautions; worried)	33 (62.30)
<b>CG secondary appraisal of available support</b>	
Sufficient formal services	31 (58.50)
Sufficient informal support	36 (67.90)
<b>CG coping strategies</b>	
Passive strategies	23 (43.40)
Active strategies	30 (56.60)

Note: CG = caregiver; Pwd = person with dementia. CG age range = 30–82 years.



**Figure 1.** The transactional model of stress. Adapted from *Transactional Model of Stress and Coping* - Richard Lazarus, by P. Guttman used under CC BY-SA 4.0 ([https://commons.wikimedia.org/wiki/File:Transactional\\_Model\\_of\\_Stress\\_and\\_Coping\\_-\\_Richard\\_Lazarus.svg](https://commons.wikimedia.org/wiki/File:Transactional_Model_of_Stress_and_Coping_-_Richard_Lazarus.svg)).

income adequacy, and race/ethnicity (Table 1). CGs also reported occurrence of PwD's memory-related behavior problems (Teri et al., 1992). Higher summed scores indicated more problematic behaviors. CGs rated three items depicting how they felt about caregiving during the stay-at-home phase (exhausted, more things to do than can handle, didn't have time for self) on a 4-point Likert scale from 0 (*not at all*) to 3 (*extremely*). The average of these items yielded a Role Overload score ( $\alpha = .73$ ;  $M = 1.61$ ; median = 1.67).

CGs responded to a series of open-ended questions about their care situation during the stay-at-home phase, how they were managing day-to-day activities and chores, challenges related to caring for PwD, and whether the pandemic had affected close relatives. Their *primary appraisal of stressors related to COVID-19* was coded as *positive*, *concerned*, or *irrelevant*. They also discussed use of paid services during this time; if services had changed due to COVID-19 crisis, they provided details about the changes, how the changes affected PwD's care, and satisfaction with the changes. Responses signified *secondary appraisal of the availability of formal services* and coded as *sufficient* (1) or *insufficient* (0).

CGs discussed whether family and friends/neighbors were helping with PwD personal care, everyday tasks (grocery shopping), and socializing with CG and PwD during the stay-at-home phase. Responses indicated *availability of informal support* and coded as *sufficient* (1) or *insufficient* (0).

CGs *coping strategies* were revealed in comments about how well they were able to manage responsibilities, have personal time, and manage PwD behavior problems. Descriptions signified *active strategies* (met problems head-on, planful problem-solving, pursued leisure activities) or *passive strategies* (withdrawing, doing nothing, avoidance, no leisure activities) (Folkman et al., 1987).

## Data Analysis

CGs were split into two groups based on their Role Overload score using median split (see [Supplementary Appendix](#)). A logistic regression model with robust standard errors (STATA V.16) examined whether CG primary appraisal of COVID-19 pandemic, secondary appraisal of resource availability (formal services and informal support), and coping strategies were associated with higher role overload, controlling for PwD's memory- and behavior-related problems.

## Results

### Primary Appraisal of COVID-19 Pandemic

Most CGs (62%) expressed concern about the pandemic and meticulously followed guidelines for keeping PwD and themselves safe from COVID-19. Yet, 26% thought the stay-at-home order did not affect their lives in any major

way. As one participant said, referring to her caregiving responsibilities,

People talk about being quarantined. Honey, I [have been] in quarantine for years now....so really, we are not having any effects from that.

Other CGs expressed annoyance because PwD were frustrated from staying home and did not understand why they could not go out.

His temper tantrum, "cause he can't go out to eat. He doesn't understand why nobody's coming to see him. And we tried to explain the coronavirus...but it's not registering...He just gets kind of mad sometimes when we go through the drive-thru and we go back home so he can eat...but after we done been out and he's done ate and stuff, 15-30 minutes [later], he's ready to go back out again because he swears he ain't been out none of that day.

A few CGs (11.3%) saw the pandemic as having benefits. CGs who were furloughed/laid off from work were able to spend more time with PwD and catch up on work around the house; others got help with caregiving from family members who were furloughed. Some mentioned that PwD appeared more at ease with the CGs being at home all the time.

### Secondary Appraisal of Formal Services Availability

CGs reported that local area agencies on aging checked on them more often than before and nutrition services (e.g., meals-on-wheels programs) delivered extra meals and provided microwave ovens to those who did not have one. Telehealth was also available if they required medical attention. Because home care providers are essential workers, home care services were not completely stopped. Although 59% of CGs rated the services they were receiving now as sufficient, a sizeable proportion (41%) expressed weariness because their care aides had reduced days or hours or stopped coming.

The home health nurse that we had has an immunocompromised son at home...and the housekeeper is not coming...we are managing. We all just kind of pitch in...I've enlisted the kids that are home out of school. They've got chores they have to do every day.

I need some more [help]; it's a little hard to find people...If they take unemployment and they were making 300 bucks a week, now they get \$600 from the government - who'd want to work? So, I lost the service because of the virus.

### Secondary Appraisal of Informal Help Availability

Although 68% of CGs received help with grocery shopping or social interactions in person or via phone and video calls, and most believed their families would help if needed,

32% were not receiving enough support from family. Some expressed frustration because they were now solely responsible for providing care.

Normally my kids would come over, or my brother and sister might come down to visit, and so they're not, you know, none of that has happened...As my mom gets worse there are more calls in the middle of the night. [Interviewer: Have family or friends been helpful...] Uh, no, nothing there at all.

### Coping Strategies

Approximately 57% of CGs used active coping strategies, with 43% using passive approaches. Active coping strategies varied, from taking some "me-time," going outside on their property alone, gardening, and making protective masks for care aides. CGs who used passive coping spent time twiddling on their cellphones, playing computer games, or could not explain whether they did anything for themselves.

### Role Overload

Table 2 displays the logistic regression results. Overall, 25 of 53 CGs (47%) reported high role overload during the stay-at-home phase of the COVID-19 pandemic. Adjusting for PwD's behavior problems, CGs who were more concerned about the pandemic were at greater odds of experiencing higher overload than CGs who recognized some positive aspects. Sufficient informal support significantly decreased the odds of reporting higher overload.

### Discussion

The COVID-19 pandemic has caused significant disruptions to everyday life. Family CGs for PwD, particularly those in under-resourced areas such as rural Virginia, face numerous challenges in caring for their relatives and managing use of any available sources of assistance and support. Understanding how they assess and react to the added difficulties imposed by the pandemic is key to helping them move through taxing situations resourcefully. Our use of theoretical concepts from the transactional stress model revealed differential appraisals of the severity and impact of the stay-at-home order on CGs for PwD in rural communities. Whereas some CGs reported that they and PwD were frustrated by limitations on daily routines, enjoyable opportunities to socialize, and reduced or terminated formal services and respite upon which they depend, others found few major changes to their already home-based and solitary lifestyle. Those who expressed deep concerns about the pandemic are especially vulnerable to poor psychological well-being due to strong feelings of role overload.

Similarly, although over half the CGs regarded availability of formal services or informal support as sufficient,

**Table 2.** Logistic Regression Model Predicting High Caregiver Role Overload

Measure	Coefficient	Robust SE	OR
CG primary appraisal of stressors related to COVID-19			
Positive (beneficial, constructive, sanguine)	-2.40*	0.98	0.09
Irrelevant (indifferent)	-0.48	0.80	0.62
Concerned (taking precautions; worried) (ref.)	-	-	-
CG secondary appraisal of available support			
Sufficient formal services	0.42	0.92	1.52
Sufficient informal support	-1.90*	0.97	0.15
CG coping strategies			
Passive strategies	-0.97	1.06	0.38
Active strategies (ref.)	-	-	-
Control variables			
PwD memory- and behavior-related problems	0.19**	0.07	1.21
Constant	-0.69	1.47	0.50
$\chi^2$ (df)	13.54 (6)		

Notes: OR = odds ratio.

\* $p < .05$ ; \*\* $p < .01$ .

CGs who were not receiving enough formal services and those who lacked informal support were at greater risk for role overload. Thus, CGs craving more support require specific attention. Because research shows that role overload is associated with poor CG health and diminished mental health (Gaugler et al., 2003) and respite programs (adult day services) are scarce in rural areas, sustaining CG health and well-being so they can continue to care for PwD is of paramount importance. By pursuing CG appraisals of the pandemic and secondary appraisals of service and support availability, we uncovered nuances related to challenges CGs faced because of the pandemic. Caution is advised in generalizing the findings because of the relatively small sample size and the unique geographical setting of rural Virginia.

Nevertheless, our findings revealed that communities demonstrated resourcefulness in striving to continue meeting CG and PwD needs (e.g., meal delivery program, telehealth) and sustaining CGs' ability to continue providing care for PwD. Even beyond the pandemic, home-delivered and internet-based services are convenient for rural families who must travel 45–60 min for specialty care clinics and sometimes basic services like banking and pharmacy (Harris et al., 2018). Expansion of broadband internet service to rural communities is essential both for managing the current pandemic with an uncertain length of restricted movement and for fostering preparedness for future challenges (Friedenberger, 2020).

## 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

None declared.

## Author Contributions

J. Savla planned the study, conducted qualitative coding and data analysis, and wrote the paper. K. A. Roberto planned the study, verified qualitative coding, and contributed to writing the paper. R. Blieszner helped plan the study and write the paper. B. R. McCann and E. Hoyt conducted participant interviews and aided in interpreting the results. A. L. Knight helped plan the study and recruit participants. All authors discussed the results and interpretation and commented on the manuscript.

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