


Dual Caregivers of Persons living with Dementia: The Added Stress of COVID-19 Pandemic

Gerontology & Geriatric Medicine
Volume 8: 1–6
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DOI: 10.1177/23337214221081364
journals.sagepub.com/home/ggm


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Abstract

Serving in dual caregiving roles presents challenges and has consequences for caregivers' physical and mental health. Forty-six dual caregivers in rural southwest Virginia participated in one semi-structured telephone interview pre-pandemic. Of these caregivers, nine dual caregivers of multiple older adults (MOA) and six caregivers of multiple generations (MG) participated in two telephone interviews during the COVID-19 pandemic. Pre-pandemic health, stress, and support data were used to compare dual caregivers of MOA and MG; differences were minimal. Responses to interviews conducted during the pandemic highlighted the effects of social restrictions on MOA and MG caregivers, revealing five themes (1) Increased isolation, (2) Increased need for vigilance, (3) Negative impact on mental health, (4) Tendency to "do it all," and (5) Increased informal help. MOA and MG caregivers differed on managing care responsibilities and ensuring the health of care recipients. In general, dual caregivers experienced decreased mental health, increased social isolation, and increased caregiving responsibilities. Antecedents of the pandemic experiences differentiated MOA and MG caregiver. Findings suggest that programs and services should target dual caregivers' unique needs.

Keywords

multigenerational family caregiving, older adults, mixed-methods, community services, rural caregivers

Manuscript received: October 20, 2021; final revision received: December 17, 2021; accepted: February 1, 2022.

Dual Caregivers of Persons with Dementia: The Added Stress of COVID-19 Pandemic

Estimates show that 24% of caregivers provide support to more than one relative (AARP and National Alliance for Caregiving, 2020). The literature on dual family caregivers of older adults focuses primarily on "sandwiched" caregivers who assist two or more generations simultaneously (Boyczuk & Fletcher, 2016; Manor, 2021), with a plethora of literature focusing on grandparents supporting adult children and raising grandchildren (Hayslip et al., 2019). Many sandwiched caregivers not only have the responsibility of providing care for two generations, but also need to manage the added complexity of working full-time to support their family financially, which can contribute additional stress in their lives (Hammer & Neal, 2008; Manor, 2021).

Some researchers investigating grandparents raising grandchildren take the "sandwiched" caregiver focus a step

further by analyzing the impact of being a "double sandwiched" caregiver who provides care not only to the generations directly above and below them but also to the generation two steps above them (Meyer, 2014). A recent study of working women, mostly in their sixties, found that juggling the demands of multigenerational caregiving had negative physical, psychological, and social impacts on the women's daily lives (Manor, 2021). Other researchers have studied "compound" caregivers

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who serve in a dual role of caring for a child with an intellectual disability as well as for spouses, parents, other children or relatives, and friends. These caregivers frequently reported being unable to concentrate (Marsack-Topolewski, 2020) and having little personal time and a lack of adequate help from others with managing their multiple, and often complex, caregiving tasks (Perkins & Haley, 2010).

While there is considerable heterogeneity in the contexts of two-generation caregiving families, little is known about caregivers who help multiple older adults, and even less research has focused on dementia caregivers in these dual caregiving roles. As providing care to more than one family member is becoming increasingly common (AARP and National Alliance for Caregiving, 2020), and the number of persons with dementia is growing rapidly (Alzheimer's Association, 2021), it is imperative to understand the needs and experiences of dual caregivers now than ever before.

Rural Caregivers and COVID-19

The COVID-19 pandemic transformed the daily lives of family caregivers. A national study of informal caregivers of individuals aged 50 years or older with physical health conditions, disability, or cognitive decline found that rural informal caregivers were more than twice as likely as urban informal caregivers to report a substantial increase in caregiver burden due to COVID-19 (Cohen et al., 2021). In general, dementia caregivers in rural areas tend to be more isolated and have less access to resources than their urban counterparts (Bouldin et al., 2017; Browna et al., 2018). During the pandemic, rural residents were even more susceptible because of lack of resources for pandemic preparedness, and lower likelihood of adhering to COVID-19-related preventative measures (Callaghan et al., 2021). Emerging evidence shows that the introduction of stay-at-home orders during the pandemic presented new challenges for rural dementia caregivers because of reduced access to community-based services (Greenberg et al., 2020), while exacerbating caregiver burden and mental health concerns (Russell et al., 2020; Savla et al., 2021).

Dual Caregivers and COVID-19

Families that were dependent on health care and community services for their older family members, as well as households with school-aged children who relied on schools and leisure activities outside of school, were particularly hard hit during the pandemic. Disruptions in both these arenas could have disproportionately affected dual caregivers, who faced challenges and complexities of the dual caregiving role even prior to the pandemic. Thus, our primary aim was to explore the experiences of dementia family caregivers of multiple older adults (MOA caregivers) compared with dementia family caregivers responsible for multiple generations (MG; i.e., caring for PwD and children or grandchildren) within the context of the pandemic. Our primary research questions asked, (1) What pandemic-

Table 1. Sample Characteristics (N = 46).

Variable	MOA		MG	
	n	%	n	%
Sex				
Female	22	81.5	16	84.2
Male	5	18.5	3	15.8
Race				
White	25	92.6	16	84.2
African American	2	7.4	3	15.8
Relationship				
Spouse	9	33.3	8	42.1
Adult child	10	37	9	47.3
Daughter in-law	3	11.1	1	5.3
Grandchild	2	7.41	0	0
Other	3	11.1	1	5.3

MOA = Caregivers caring for multiple older adults; MG = Caregivers caring for multiple generations

related challenges and stressors were faced by MOA and MG caregivers living in rural areas? and (2) What are the physical and mental health implications of dual caregiving?

Methods

Sample

The original sample included 124 family caregivers caring for PwD (Savla et al., 2022). We focused on the 46 caregivers who provided care for a PwD and also another relative: 27 MOA caregivers and 19 MG caregivers (see Table 1 for demographic characteristics). Participants were recruited for this study using convenience sampling methods. Participants identified through the local agencies on aging and through a local health system were then contacted by the research team via telephone for recruitment. Persons were eligible for the study based on residency in Southwest Virginia for at least 15 years and provision of care to someone with dementia at least 4 days a week. Once determined eligible, participants gave informed consent to be interviewed (see Savla et al., 2022, for detailed description of the study methods).

Data Collection

We conducted three telephone interviews. During the first interview, approximately 20 months before the pandemic onset, participants responded to structured questions about themselves and their caregiving experiences, including self-assessed health compared to others their age, perceived family support, and secondary stressors not directly related to caregiving (e.g., personal health problems, financial worries, relationship problems). Questions in this interview included forced rating scales (see Savla et al., 2022). For example, caregivers were asked to rate their perceived family support as "Not at all," "A little," "Some," or "A lot."

Table 2. Pre-pandemic Self-Rated Health, Support, and Stress of Caregivers.

Variable	Range	MOA Mean	MG Mean	<i>p</i>
Self-rated health	[1–3]	1.67	2.21	0.04 ^a
Family support	[1–4]	2.97	3.16	0.23
Secondary stressors	[0–40]	8.41	7.58	0.20

MOA = Caregivers caring for multiple older adults; MG = Caregivers caring for multiple generations

^a*p* < .05

Approximately a month after the stay-at-home order was announced in Virginia, fifteen of the participants completed two semi-structured telephone interviews spaced four to 6 weeks apart; these interviews focused on how the pandemic and stay-at-home order affected their caregiving situation. Open-ended questions for these interviews were developed, based on the previously reported caregiver experiences, to inquire about changes that occurred to participants' caregiving situations because of the pandemic. Caregivers described precautions they were taking to prevent contracting COVID-19, the pandemic's impact on formal and informal help, and personal and secondary stressors. The goal of these questions was to obtain a detailed picture of the caregivers' experiences during the pandemic.

Data Analysis

Pre-pandemic data were analyzed using a Wilcoxon rank-sum test to compare the MOA and MG caregivers on self-assessed health, perceived family support, and secondary stressors. Recorded responses to the pandemic interview questions were transcribed verbatim and verified, then transcripts were read multiple times. Based on a directed content analysis approach (Hsieh & Shannon, 2005), we used a three-phase process to code the interviews: (1) Identified concepts from previous dual caregiver research and noted their manifestation during the pandemic for each type of dual caregiver (e.g., caregiver burden). (2) Applied codes developed from open-coding sessions (e.g., impact on informal help). (3) Developed new codes for emergent concepts (e.g., caregiver disposition such as "doing it all"). The coded transcripts were then analyzed to identify themes that characterized similarities and differences across MOA and MG caregivers. Transcript analysis was conducted by the lead author, followed by review and discussion of themes and codes by three of the co-authors to resolve any disagreements in interpretation and ensure confirmability.

Results

Pre-Pandemic Comparisons

Pre-pandemic data showed minimal differences between the two types of dual caregivers on their personal characteristics. Table 2 presents the only pre-pandemic difference

between the two types of dual caregivers. Compared to MOA caregivers, MG caregivers rated their health as poorer than others their own age. Both groups reported similar family support and secondary stressors, and both used at least one home and community-based service at about the same rate before the pandemic (MOA = 41%, MG = 37%). When reviewing quantitative data alone, MOA caregivers and MG caregivers in this study did not show many significant differences.

Caregiving During the Pandemic

Fifteen dual caregivers (MOA = 9; MG = 6) participated in the telephone interviews during the pandemic. MG caregivers were slightly older (Mean Age = 65.83, SD = 13.62) than MOA caregivers (Mean Age = 58.89, SD = 8.22). The majority of the dual caregivers were White (MG = 67%; MOA = 89%) and were women (MG = 83%; MOA = 89%). Analysis of the interviews revealed five major themes: (1) Increased isolation of caregiver, (2) Increased need for caregiver vigilance, (3) Negative impact of COVID-19 on caregiver mental health, (4) Tendency to "Do it all," and (5) Positive influence of COVID-19 on informal help. Within each theme, both commonalities and unique differences in caregiving experiences emerged between MOA and MG caregivers Table 3. The differences were largely due to variations in the antecedents of the pandemic experiences and stressors.

Increased Isolation

Six MOA (67%) and four MG (67%) caregivers reported feeling increasingly isolated since the start of stay-at-home orders. They regretted their inability to see family and friends and felt stuck at home. The minimal amounts of socializing they were able to enjoy before implementation of the stay-at-home order were no longer possible because of restrictions on group gatherings. As one MOA caregiver explained, "We enjoy going out to eat. That's one of the biggest things that we miss, is going out to eat, and social gatherings."

While both groups of dual caregivers reported social isolation, they differed in their response. MOA caregivers were more likely to report engaging in socially distanced visits with friends and family, whereas MG caregivers tended to engage with friends and family via technology (video chatting, phone calls). Their approaches may be explained by generational differences in comfort level with social media and technology. MG caregivers had the advantage of living with young or teenage children in the home who often were technologically experienced.

Need for Vigilance

Both MOA (*n* = 7, 78%) and MG (*n* = 5, 83%) caregivers reported being on high alert to protect themselves and their loved ones. Their vigilance encompassed activities and

Table 3. Dual Caregiver Experiences During the Pandemic.

Themes of Caregiver Experience	Common Dual Caregiver Experiences	Unique Dual Caregiver Experiences	
		MOA	MG
Increased isolation	Inability to see family and friends due to the pandemic Even minimal amounts of socializing were no longer an option	Engage in socially distanced visits	Engage in visits via technology
Increased need for vigilance	Decreased visits with friends and family reduced engagement with the “outside world.”	Worry about interactions within health care facilities	Worry about interactions of younger care recipient with other children
Negative impact on mental health due to lack of self-care	High levels of caregiving-related stress and fewer opportunities to practice self-care	Attributed lack of self-care to having too many responsibilities	Attributed lack of self-care to inadequate alone time
Tendency to “do it all”	Need to do everything for care recipients Experienced increased dual caregiving tasks	Assisted older adults with personal care activities	Assisted younger care recipient with schooling
Increased informal help	Reported increased informal help from friends and family	Help from adults who lived elsewhere	Help from younger care recipient with PwD.

MOA = Caregivers caring for multiple older adults; MG = Caregivers caring for multiple generations; PwD = Person with dementia

behaviors that decreased the risk of the PwD contracting COVID-19, including reducing visits with friends and family, decreasing engagement with the “outside world,” and ensuring that individuals coming into the home practiced recommended safety procedures. Although some caregivers reported reduced frequency of services, and a few PwD were no longer able to attend the adult day center, most caregivers did not necessarily lose in-home services because providers were considered essential workers. Caregivers instead had issues with formal and informal helpers meeting the caregivers’ standards for reducing COVID-19 exposure for the PwD, and felt they needed to be vigilant about paid helpers’ hygiene practices in the home. For example, caregivers made sure visitors wore proper personal protective equipment and maintained social distancing when possible.

Conversely, MG caregivers worried about the risk from interactions of their younger care recipient with other children. As one MG caregiver described:

I’ve tried to keep everybody away that could bring [COVID-19] in. And you can carry this stuff and not know it... We are afraid that somebody will be a carrier, not know it, and he [PwD] wouldn’t survive it...

Differences in the potential sources of the virus transmissions explains the variations in vigilance in the two groups.

Negative Impact on Mental Health

Both groups of dual caregivers described high levels of stress from the stay-at-home order (MOA = 6, 67%; MG = 3, 50%). Although they recognized the importance of self-care, they felt unable to engage in these activities because of caregiving demands. As one MOA caregiver noted, It’s just really

difficult. I think that I have to be reminded and put as much emphasis on taking care of myself as I have on my mom, and it’s not always possible. But I try to remember that if I do not take care of myself, I can’t take care of her. Just with everything that’s going on and, on the news, constantly, all the problems, it just adds more stress to your life in general.

While both types of caregivers shared perspectives about self-care, they had different reasons for not engaging in those activities. MG caregivers attributed lack of self-care to insufficient alone time from having too many people in their home. MOA caregivers explained their lack of self-care in relation to increased caregiving responsibilities and demands on their time.

Tendency to “Do It All”

The tendency to “do it all” was a common self-perceived disposition among MG ($n = 3$; 50%) and MOA ($n = 5$; 56%). Dual caregivers felt responsible for providing the majority of care needed by their family members and perceived an increase in dual caregiving tasks due to the pandemic. A MG caregiver reflected on her struggle to manage the competing demands of her dual role along with increased responsibilities:

Finding the time is what it’s been, and feeling like I’m not taking time away from the husband or grandchildren or [PwD]. ...The thing that’s happened is now, since we have my granddaughter here and our son, it’s a little bit different than it was before, because we’re all in the house together, and I’m the only one that’s going out and coming back.

Dual caregivers differed in extra tasks they assumed during the pandemic, based on their care recipients’ needs. For example, in addition to the daily care they provided to the PwD, MG caregivers assisted their younger care recipient with activities

such as online schooling. In contrast, MOA caregivers now assisted the PwD with grooming activities, such as hair and nail care.

Increased Informal Help

Navigating the pandemic also had positive impacts on these families. Dual caregivers (MOA = 5, 56%; MG = 3, 50%) reported receiving increased help from friends, family, and neighbors, compared to before the pandemic, for specific tasks that would have otherwise required them to leave home. Family and friends rallied during the pandemic to ensure they had the resources they needed to get through the stay-at-home order as easily as possible. Informal help for MOA caregivers included others delivering supplies, groceries, and other items (hand sanitizer, toilet paper). MG caregivers were able to take advantage of their dual caregiver role by having the child in their home to help with caregiving tasks for the PwD:

[We are] just managing. Mom's aide is still here. So, we all just kind of pitch in and I've enlisted the kids that are home [because of being] out of school. [They are] in kindergarten and first grade. They've got chores that they have to do every day. So, everybody's just kind of picking up a little bit.

Yet, even with the help received from informal helpers and family members within the household, the bulk of caregiving responsibilities for the PwD fell on the caregivers.

Discussion and Implications

Our focus on the experiences of dual dementia caregivers, their care responsibilities, and stress during the pandemic revealed that MOA and MG caregivers were challenged to manage social isolation, reduce the risk of COVID-19 to household members, and assume extra care-related tasks for the PwD and other dependents. Consistent with the emerging literature on the pandemic's impact on caregivers (Russell et al., 2020; Savla et al., 2021), additional responsibilities increased the caregiver's feelings of stress. Contrary to findings of increased social isolation during the pandemic (Holt-Lunstad, 2021), the dual caregivers in our study focused instead on difficulties in maintaining or initiating self-care activities because of not enough alone time or too many chores.

In contrast to reports of reduced access to formal services (Greenberg et al., 2020), the dual caregivers in our study did not experience difficulties from loss of or reduced access to formal services. However, they made numerous changes to caregiving routines to lessen the risk of COVID-19. Similar to caregivers of a single older adult or an adult with disabilities (Lightfoot et al., 2021), dual caregivers avoided using some services to limit the family's exposure to outsiders and exercised vigilance to manage their relatives' interactions with formal service providers who did enter the home.

Our study also revealed that the pandemic had a unique impact on caregiving stress depending on the type of dual

caregiving role. These variations can be explained by the differing ages of the care recipients, with MOA caregivers performing more personal care activities for both older adults, whereas MG caregivers provided instrumental support such as schooling or baby-sitting to the younger generation and personal care assistance to the person with dementia. Regardless of the types of care responsibilities caregivers managed, our findings suggest that dual caregivers are a particularly vulnerable group. They are very likely to experience a higher cost of caregiving because of increased vigilance, expansion of responsibilities, feeling that they were solely responsible for the hands-on care, and insufficient time or space for self-care.

Organizations and agencies that serve dual caregivers need to consider the impact caring for more than one person can have on a caregiver. Our findings suggest that dual caregiving added complexity to the caregivers' role and responsibilities due to the multifaceted nature of their caregiving situation. Caregivers in our study found themselves isolated and alone during the pandemic. Community organizations, such as Area Agencies on Aging and other senior services, as well as grocery stores, schools, and libraries should offer additional social support programs for caregivers who provide care to more than one individual, and funding agencies should provide increased funding opportunities for organizations to develop and implement social support programs such as buddy program or support groups. Further, increasing support for consumer-directed programs to allow caregivers the flexibility to make services work for them and their needs is warranted. Dual caregivers in our study relied heavily on family and friends, and often worried about formal workers not providing the level of care they felt was appropriate. By enhancing consumer-directed programs in which caregivers can either be paid directly for the care they provide or hire a family member to assist, caregivers would have more freedom to make decisions about the PwD care and decreased need to be "on duty" constantly.

Dual caregivers are a growing group of individuals who experience caregiving differently than traditional caregivers. More research should be conducted to deepen understanding of these differences and to develop additional recommendations for supporting all types of dual caregivers. This study focused on rural caregivers that were mostly White and women; caregiving experiences may have been less stark among diverse and urban caregivers with access to varied resources and support. Nevertheless, these comparisons across two types of dual caregivers are fruitful in revealing nuances in the population of family caregivers that warrant further exploration beyond the pandemic. Given inability to predict the post-pandemic "new normal" regarding availability of and access to formal services, it is important to promote informal assistance to multiple types of dual caregivers while developing suitable formal services and delivery systems for them.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the National Institute on Aging (R21AG054682) and Virginia Tech's COVID Rapid Response Fund.

Author's Note

This study was approved by the Carilion Clinic IRB (#2284).

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