Racial Differences in the Dementia Caregiving Experience during the COVID-19 Pandemic: Findings from the National Health and Aging Trends Study (NHATS)

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Abstract

Objectives

Given racial disparities in both dementia and COVID-19, non-Hispanic Black (Black) dementia caregivers (CGs) may be at greater risk for care burden during the COVID-19 pandemic than non-Hispanic White (White) CGs. This study investigates the impact of dementia care provision on CGs' quality of life by race using the 2020 National Health and Aging Trends Study (NHATS) Family Members and Friends COVID-19 data (FF).

Methods

This study features a secondary analysis of FF data (2020–2021), including 216 Black and 1,204 White CGs. We used ANOVA to determine differences in caregiving stressors (i.e., changes in providing help with activities of daily living [ADL], instrumental ADL [IADL], and emotional support). OLS regression was used to investigate the moderating effects of dementia care on the associations of race with perceived well-being, care burden, and self-reported health and to conduct subgroups analyses of Black and White dementia CGs.

Results

Black dementia CGs provided significantly more help with ADL before and during the COVID-19 pandemic than Black non-dementia, White dementia, and White non-dementia CGs. Dementia care status did not moderate the associations between race and CG outcomes. For Black dementia CGs, changes in objective stressors (assistance with ADL and IADL) were associated with care burden and well-being. For White CGs, the provision of emotional support was associated with care burden and well-being.

Discussion

This study highlights increased caregiving demands during the pandemic amplified racial differences in CG stress. Findings suggest that outreach to reduce CG stress and burden is critical for Black dementia CGs.

Keywords: Alzheimer's and other dementias, race, care burden, well-being, health, COVID-19 outbreak

Introduction

The outbreak of Severe Acute Respiratory Syndrome Coronavirus-2 and the ongoing coronavirus disease (COVID-19) pandemic created unique financial, health, and emotional challenges for persons with dementia (PwD) and their family caregivers (CGs). A recent systematic review and meta-analysis found dementia is a salient risk factor for severe COVID-19 infection, as well as for poorer outcomes and elevated mortality due to COVID-19 (Hariyanto et al., 2021). CGs to PwD have reported concerns about spreading the disease to their care recipients (CRs) (Lightfoot et al., 2021), and there is evidence of increased caregiving intensity, stress, and burden during the COVID-19 crisis (Archer et al., 2021; Budnick et al., 2021; Cohen et al., 2021; Lightfoot et al., 2021).

The effects of the ongoing pandemic are especially detrimental to communities of color due to structural racism and other systemic issues that increase the risk for COVID-19 exposure, pre-existing health disparities, and limited access to trustworthy and high-quality medical care (Garcia et al., 2020). The pandemic also intensified racial and ethnic disparities in social networks through social distancing measures that restrict face-to-face interactions and can limit diverse social networks that assist dementia CGs with informal and formal support (Gauthier et al., 2020). Thus, understanding the intersections of race and the dementia caregiving experience during the COVID-19 pandemic is key to identifying high-impact intervention points both post-pandemic and as the crisis continues.

COVID-19, Dementia, and Caregiving

COVID-19 has posed formidable challenges for PwD in hospital, outpatient, care home, and community settings (Mok et al., 2020). Dementia symptoms such as impairments in executive function can limit understanding and compliance with public health recommendations like mask-wearing, regular handwashing, and social distancing (Cipolletta et al., 2021). Neuropsychiatric behavioral expressions related to dementia such as agitation and wandering also heighten the risk

for both contracting and spreading COVID-19. There is evidence that for PwD, the pandemic has increased feelings of isolation and abandonment; exacerbated neuropsychiatric symptoms of dementia such as anxiety, agitation, and mood disturbances; further decreased cognition and communication; and increased dependence with activities of daily living (ADL) (Borges-Machado et al., 2020; Goodman-Casanova et al., 2020; Simonetti et al., 2020).

The latter change witnessed during the pandemic–increased ADL dependence–for PwD and other chronic conditions may be particularly salient to CGs. The degree of CRs' dependency in ADL and instrumental ADL (IADL) is a predictor of CG burden (Lin et al, 2019; Rodríguez-González et al., 2021). Lin and colleagues (2019) studied further nuances in this association in a group of dementia CGs by analyzing hours spent assisting with different types of ADL (i.e., basic ADL vs IADL). Whereas they found inconsistent associations between CG burden and hours of IADL assistance, more care provided with basic ADL was linked to CGs' higher level of perceived burden. The team concluded that additional emphasis on providing respite care to dementia CGs who are supporting basic ADL needs is important to consider.

Notwithstanding the increased need for assistance, emerging evidence suggests COVID-19 has interrupted formal services and support for PwD. Early lockdowns reduced access to care, delaying and disrupting assessments, treatment, medication maintenance, and other types of care such as cognitive rehabilitation. Community-based services such as senior centers, adult day centers, and home health services were also limited (Barry & Hughes, 2021; Giebel et al., 2021; Mok et al., 2020). Although some services eventually adapted to meet this context (e.g., virtual session offerings), perceptions of the suitability, quality, and accessibility of these were mixed, particularly regarding whether doing so introduced new inequities (Giebel et al., 2021).

Although some CGs experienced the COVID-19 context as an opportunity to slow down and spend more time with CRs, deepening their relationships (Cipolletta et al., 2021; Lightfoot et al., 2021), many perceived their care situations as worsened during the pandemic (Budnick et al., 2021).

Interruptions or discontinuation of service, coupled with limited access to other sources of informal support due to social distancing, have necessitated many family CGs to assume additional care responsibilities (Cipolletta et al., 2021; Greenberg et al., 2020). This has led to increasing caregiving intensity and/or time spent on caregiving responsibilities (e.g., providing more help with ADL/IADL, having to offer additional emotional support to PwD). Secondary CG stressors have been amplified too, including the financial stress of dementia caregiving due to layoffs, furloughs, and workplace shutdowns (Ercoli et al., 2021; Greenberg et al., 2020). Moreover, challenges related to school closures have increased demands on the "sandwich generation" or those providing care to both children and older adults.

The effect on CGs' psychological well-being is apparent. A systematic review of 10 studies—all conducted outside the U.S.—of the impact of the pandemic on dementia CGs highlighted the negative impact on CGs' mental health in terms of depression and anxiety (Hughes et al., 2021). Even simple tasks like running errands became anxiety-inducing for CGs given the fear of virus exposure for themselves and their CRs (Ercoli et al., 2021). The current study contributes to this area of research by examining CGs' stress, health, and well-being during the COVID-19 pandemic by utilizing the 2020 COVID-19 Family Members and Friends (FF) data of the nationally representative National Health and Aging Trends Study (NHATS) and by focusing on the intersection of race and dementia care. .

COVID-19, Dementia Caregiving, and Race

Black older adults are approximately twice as likely to live with dementia compared with older Whites (Alzheimer's Association, 2021). They are also at greater risk for contracting and dying from COVID-19 (Gold et al., 2020). Consequently, Black PwD are at high risk for COVID-19 infection, more so than their White counterparts, even when controlling for medical risk factors (Wang et al., 2021). Such health disparities within the dementia-COVID-19-race nexus reflect structural racism

and systemic issues facing communities of color (Alzheimer's Association, 2021; Garcia et al., 2020; Khazanchi et al., 2020).

Limited research is available on the impact of the pandemic on racial minority dementia CGs. Separate from the COVID-19 context, examining Black dementia CGs' overall well-being reveals conflicting findings. Some research shows an increased risk for depression in Black dementia CGs (Alzheimer's Association, 2021), whereas other studies report Black CGs' greater resilience and positive attitudes toward caregiving, with similar or slightly better levels of psychological well-being (Alzheimer's Association, 2021; Dilworth-Anderson et al., 2020; Liu et al., 2021). Nevertheless, Black informal CGs do report more time-demanding caregiving situations (e.g., having to assist with numerous ADL) than Whites and less formal help utilization (Alzheimer's Association, 2021; Rote et al., 2019; Rote & Moon, 2018). Importantly, the pandemic has increased racial disparities in marginalized groups' social networks (Gauthier et al., 2020). Because social support from others is more closely linked to the health of Black CGs than for other racial and ethnic groups (Rote et al., 2019), the health-protective value Black dementia CGs can garner from informal social support has been threatened.

Despite the potential disparities in dementia care among Black CGs of PwD compared with Whites during the pandemic, no study has examined the impact of dementia care provision on CGs' comprehensive well-being by race within the context of COVID-19. The present study will address this gap. Informed by the caregiver stress and coping model (Aranda & Knight, 1997; Lawrence, et al., 1998; Pearlin et al., 1990; Sörensen & Pinquart, 2005), we utilize data on dementia and non-dementia CGs from NHATS COVID-19 FF data (2020–2021). Given the evidence that COVID-19 conditions have intensified pre-existing inequities in socioeconomic well-being, technology, access to care and support for PwD and their families, and other health disparities (Ercoli et al., 2021; Giebel et al., 2021; Gold et al., 2020; Van Houtven et al., 2020), we expect to find the following:

Hypothesis 1 (H1): Non-Hispanic Black (Black) dementia CGs will report the highest levels of primary objective stressors (i.e., provision of help for activities of daily living [ADL], instrumental activities of daily living [IADL], and emotional support), as well as worse CG outcomes (i.e., more perceived care burden and worse psychological well-being and self-rated health) during the COVID-19 outbreak compared with other CG groups (i.e., Black non-dementia CGs and White CGs).

Hypothesis 2 (H2): Black dementia CGs will report a) more changes in the provision of ADL and IADL help from pre- to during the pandemic, and b) more provision of help with ADL and IADL during the pandemic compared with other CG groups.

Hypothesis 3 (H3): Dementia care status will moderate the associations between race and CG outcomes (i.e., perceived care burden, psychological well-being, and self-rated health), such that Black dementia CGs will report worse outcomes in the face of dementia care.

Exploratory Hypothesis 4 (H4): Different factors (i.e., background, stressors, and coping resources) will be associated with CG outcomes for Black and White dementia CGs.

Methods

Data

The current study used the National Health and Aging Trends Study's (NHATS) Family and Friends (FF) Files (2020–2021). The NHATS is a nationally representative study of Medicare beneficiaries 65 years and older based on annual data collection on age-related changes in physical, cognitive, psychological, and social functions. In 2020, the NHATS conducted a supplemental mail study with Medicare beneficiaries who completed Round 10 interviews. Adult family members and friends who provided assistance to the older adult during COVID-19 were identified and were mailed a questionnaire between July 2020 and January 2021. Data were collected through March 2021.

Respondents were queried about their help provision experiences during the pandemic, as well as dementia caregiving experiences, when relevant. The response rate was 64.2% (Freedman & Hu., 2020). A total of 2,062 family members or friends participated in the NHATS COVID-19 FF survey. We excluded CGs who provided care for the NHATS participants living in a nursing home or other residential care facilities. Hispanic and Other CG groups were also excluded in the current study due to the small sample sizes for dementia caregivers in these groups. Thus, we included 1,420 informal CGs. Details about the sampling design, sample weights, and variables are available (Freedman & Kasper, 2019).

Dependent Variables

Perceived Care Burden

CGs were asked how much they agreed with four statements of challenges due to helping CRs during COVID-19 in a typical day (e.g., "I have had more things to do than I can handle") using response categories from 1 (*not so much*) to 3 (*very much*). Total scores range from 4 to 12; higher scores indicate greater perceived burden of care (α=.99).

Psychological Well-Being

We used three items to assess participants' perceived well-being (e.g., "During the COVID-19 outbreak, in a typical month, how often have you felt cheerful?") using response categories from 1 (*never*) to 5 (*every day*). Total scores range from 3 to 15, with higher scores indicative of better well-being (α=.93).

Self-Rated Health

Participants were asked about their perceived general health, with response categories from 1 (*poor*) to 5 (*excellent*).

Independent Variables

Race

The NHATS categorized self-reported race as non-Hispanic White and non-Hispanic Black (referred to below as "White" and "Black," respectively).

Dementia Care

CGs were asked, "Did you help the NHATS participant, before or during the COVID-19 outbreak, because they have memory problems, including Alzheimer's disease or other kinds of dementia?" If the response was "yes," we coded it as a dementia CG (=1).

CG Primary Objective Stressors

Assistance provided with ADL and IADL is considered a primary objective stressor (Pearlin et al., 1990). CGs were asked if they helped CRs with nine ADL (e.g., bathing, getting dressed, eating) before and during COVID-19 (*yes*=1; *no*=0). Reported assistance for five IADL (e.g., doing laundry, handling bills) was scored similarly. We summed responses for the total ADL (range from 0 to 9) and IADL (range from 0 to 5) scores of help provision before and during the COVID-19 outbreak.

Changes in Help with ADL and IADL before and during the Pandemic

Changes in help over the pandemic were operationalized in two different ways: absolute difference and direction of the difference. Absolute difference represents the magnitude of change and is conducive to depicting varying gradations of extreme scores (Davis, 1993; Horowitz et al., 2004; Moon et al., 2017). For the present study, it answers the question, "To *what extent* do various CG groups' experiences in changes in help provision from pre-pandemic to amidst the pandemic differ, if at all?" For example, Black CGs of PwD may report more drastic changes than other CG groups in the number of ADL with which they helped following the pandemic onset, regardless of whether that meant they were now providing assistance with greater or fewer ADL. Direction of

difference, on the other hand, represents the nature of change observed. It can answer the follow-up question, "How does the directionality of various CG groups' experiences in changes in help provision differ, if at all?" Operationalizing changes in help provision in both ways is useful for (1) providing a complete picture of changes in care provision among CG groups relative to the pandemic onset; (2) uncovering nuanced patterns in those changes among CG groups, including each operationalization's unique associations to CG outcomes; and (3) identifying CGs most in need of intervention.

Absolute difference in help provision between pre-pandemic and during the pandemic timepoints was calculated with the formula: |*During COVID-19* score – *Before COVID-19* score|. To identify the direction, we created two dummy variables for each help measure (*ADL* or *IADL*): the first was coded "1" if the *before COVID-19* score was higher than the CG's answer, otherwise, 0; and the second was coded "1" if the *during COVID-19* score was higher than the CG's answer, otherwise 0. Consequently, the reference group was CGs, in which there was no difference before and during the COVID-19 outbreak.

Emotional Support Provided to CR

One item assessed emotional support and included the level of advice, encouragement, and emotional support offered to CRs during COVID-19. Responses range from 1 (*never*) to 5 (*at least daily*), with higher scores indicating a higher level of emotional help provided. Pre-COVID-19 values were not available to measure change.

Coping Resource

We used four items to assess CGs' *relationship quality with CRs* which serves as a CG coping resource (Häusler et al., 2016; Quinn et al.., 2009; Rippon et al., 2020); response categories range from 1 (*a little*) to 3 (*a lot*). Total scores range from 4 to 12. Higher scores indicate better relationship quality (α=.71).

Background Factors

We included CG self-reported age, sex (*male*=0, *female*=1), education (*high school or less*=0, *some college or higher*=1), and relationship to CR (*non-spouse*=0, *spouse*=1).

Analytic Strategy

First, we conducted descriptive statistics of the demographics and study variables among the total sample and by race and dementia care status (Table 1). Significant differences are based on analysis of variance (ANOVA) tests with post-hoc partitioning for comparisons between four subgroups. Then, separate regressions of perceived care burden, psychological well-being, and self-rated health by key independent variables were estimated. We estimated the variance inflation factors of the models to assess for multicollinearity and all estimates were under 2. Next, we fit ordinary least squares (OLS) multiple regression models of outcomes with the absolute and direction of differences in ADL and IADL before and during the pandemic, shown in Tables 2 and 3 respectively. Similar methods have been used in Moon et al., 2017. Within these tables, Model 1 adjusts for demographic variables, Model 2 adds stressors and a coping resource, and Model 3 adds a race*dementia care interaction effect. Finally, we present OLS regression models of CG outcomes by CG stressors (Model 1 with absolute differences in ADL and IADL, Model 2 with the direction of differences in ADL and IADL) and a CG coping resource controlled for background factors, limited to Black and White dementia CGs (Tables 4 and 5, respectively).

The primary focus of the current study is to understand the changes in the types of help with ADL and IADL and the impact on CG's quality of life before and during the pandemic by race and dementia status. We present the changes and the associations between the help and CGs' quality of life in the tables of this manuscript. In addition, we included the hours per week of caregiving by race and dementia status before and during the pandemic as Supplementary Tables.

Results

Characteristics of the Study Sample

Table 1 presents proportions and means of demographic characteristics and study variables among the total sample and for the four groups by race and dementia care status. The mean age for the groups was between 57 and 64 years old. The Black dementia CG group was younger than the other three groups (i.e., Black non-dementia CGs, and White dementia and non-dementia CGs). More than two-thirds of participants reported having some college education or higher. A large proportion of respondents were non-spouses (adult children), particularly Blacks.

In general, all CGs reported helping more with ADL and IADL following the COVID-19 pandemic onset (Table 1). Dementia CGs were likely to report providing more help with ADL and IADL before and during the outbreak than non-dementia CGs. As anticipated (*H1*), ANOVA results showed that amidst the pandemic, Black dementia CGs provided significantly more help with ADL (F (3, 1,416)=5.39 p<.001) and IADL (F (3, 1,386)=6.8 p<.003), and a significantly higher level of emotional support to their CRs than other groups (F (3, 1,386)=6.8, p<.001). They also reported the highest perceived care burden (F (3, 853) =7.22, p<.001) and worst psychological well-being (F (3, 1,416)=2.57, p<.05) and self-rated health during the COVID-19 pandemic compared with the other groups (F (3, 1,383)=11.28, p<.001).

H2 was only partially supported. As shown in Table 1, unexpectedly, White dementia CGs showed significantly more changes in help with ADL pre-to-during-pandemic (F (3, 1,332)=9.15 p<.001). Black dementia CGs, on the other hand, experienced more changes in help provision with IADL when comparing pre-versus during the pandemic than other groups, although this was not statistically significant. Regarding the direction of differences and as hypothesized, more Black dementia CGs were likely to report *more* help provision with ADL, whereas more White dementia CGs were likely to report *less* provision of help with ADL during the COVID-19 outbreak when

comparing the CG groups. Results also showed, unexpectedly, Black non-dementia CGs were likely to report providing *less* help with IADL (*F* (3, 1,461)=2.6, p<.05) and White non-dementia CGs were likely to provide *more* help with IADL (*F* (3, 1,430)=2.02, p<.05) during the outbreak compared with the other groups.

[Table 1 HERE]

Regression Analysis

Race, Dementia Care, and Care Outcomes with Full Sample

  Absolute Differences in Help. Table 2 first presents OLS regression models of CG outcomes after adjusting for background factors (Model 1), showing CGs who provided dementia care reported significantly greater perceived care burden. In addition, Black CGs reported significantly better psychological well-being but worse self-rated health compared with White CGs. These significant differences in dementia care and race remained when adding stressors and a coping resource (Model 2) to the model. However, after the interaction effect was added (race*dementia care; Model 3), no interaction effects of dementia care status by race were observable (Model 3), suggesting that *H3* was not supported and that dementia care status and the association with CG outcomes does not significantly vary for Black and White CGs.

  Regarding specific stressors, changes in the absolute difference in ADL provision from the pre-pandemic level were not significantly associated with CG outcomes. However, there was a significant effect of absolute difference in IADL, such that increases in reports of provision of IADL support during the pandemic were significantly associated with greater perceived care burden and lower psychological well-being. Additionally, a higher level of emotional support provision to CRs was positively associated with more perceived care burden. Relevant to relationship quality as a coping resource, CGs who reported better relationship quality with CRs also reported significantly better psychological well-being.

[Table 2 HERE]

Direction of Differences in Help. In the next step of the analysis, we assessed the direction of differences in help rather than absolute differences in care provision. Similar factors were significantly associated with CG outcomes, including race, dementia care status, and relationship quality with CRs; however, interesting patterns in stressors emerged. Unlike the findings with an absolute difference, more provision of ADL help during the pandemic was significantly associated with greater perceived care burden. Surprisingly, CGs who reported *less* provision of help with ADL during COVID-19 report significantly *lower* psychological well-being. For IADL, only more provision of IADL assistance during the COVID-19 pandemic was associated with significantly lower psychological well-being. None of the help with ADL or IADL categories was significantly associated with self-rated health.

[Table 3 HERE]

Regressions among Black and White Dementia CGs

In the final step of the analysis and to address *H4*, we conducted subgroup analyses among Black (Table 4) and White dementia CGs (Table 5). As hypothesized, primary objective stressors and coping resource were associated differentially with CG outcomes for Black and White dementia CGs. In terms of absolute differences in ADL/IADL support, significant differences were only observed for Black dementia CGs, specifically with IADL. An increase in providing help with IADL was significantly associated with more burden and worse self-rated health for Black dementia CGs.

For the direction of difference findings, less help with ADL during the pandemic was associated with a lower burden for both Black and White dementia CGs. More help with ADL, however, was only significantly associated with CG outcomes for Black dementia CGs. Black dementia CGs who reported an increase in ADL help provision during the pandemic reported significantly more burden and lower psychological well-being. For IADL, interestingly, the direction of

change in care provision was not significantly associated with CG outcomes for White dementia CGs; however, for Black dementia CGs, both *less* and *more* help with IADL was associated with greater perceived care burden.

For emotional support, White dementia CGs reported more burden for greater support provided but also better psychological well-being. For Black dementia CGs, emotional support provision was associated with significantly better self-rated health. For relationship quality, Black dementia CGs with better relationship quality with their CRs reported less burden, greater well-being, and slightly better self-rated health. Better relationship quality was associated with greater well-being and better self-rated health for White dementia CGs.

[Table 4 HERE]

[Table 5 HERE]

Discussion

Our findings contribute to our understanding of the impact of the COVID-19 pandemic on CG health and burden by both race and dementia status. Using a sample of CGs from a national dataset of adults 65 years and older in the U.S., along with outcomes framed through caregiver stress and coping models, our findings revealed both the significant changes in care provision and the complexity of the nature of those changes in help provision before and amidst the pandemic for various CG groups. Analysis of absolute and direction of differences of CG stressors held distinct associations with CG outcomes. First, CGs overall experienced an increase in stressors in relation to the pandemic, and those dementia CGs provided *more* help with ADL and IADL, corroborating recent findings on increased dementia CGs' challenges during COVID-19 (Archer et al., 2021; Budnick et al., 2021; Cohen et al., 2021; Helvaci Yilmaz et al., 2021; Lightfoot et al., 2021). The current study contributes to this body of research by revealing significant differences between Black dementia CGs and other CG groups.

During the pandemic, Black dementia CGs experienced the highest level of objective stressors and worse CG outcomes than the other three CG groups (Black non-dementia CGs, White dementia CGs, and White non-dementia CGs). Consistent with the literature on racial disparities in CG intensity pre-pandemic (Cohen et al., 2019; Rote & Moon, 2018), during the COVID-19 pandemic Black dementia CGs reported the most provision of ADL, IADL, and emotional support to care recipients relative to other groups. Although reports have shown Black dementia CGs as having higher levels of psychological well-being (Liu et al., 2021) and self-rated health with a long-standing CG role (Rote et al., 2019), this was not observed in the COVID-19 context. Instead, the mental well-being and self-rated health of Black dementia CGs were lower than other CG groups during the pandemic. Others have shown traditionally resilient individuals pre-pandemic were especially susceptible to the negative effects the crisis inflicted on dementia CGs (Altieri & Santangelo, 2021). This may be a reflection of the unique factors of the COVID-19 situation, with first-time challenges for many (e.g., lockdown, quarantining) that threatened the support systems on which CGs had typically relied.

The changes in stressors—including both the magnitude of changes and nature of those changes—experienced during COVID-19 were somewhat unexpected. For example, with regards to absolute difference, we observed that White dementia CGs reported the most changes in ADL provision, whereas Black dementia CGs reported the most changes in the provision of IADL support (although non-significant) compared with the other groups. When examining the direction of differences of these specific stressors, Black dementia CGs were most likely to provide *more* help with ADL, whereas their White counterparts were most likely to provide *less* help with ADL during COVID-19. Possibly, as previous research suggests, White dementia CGs may have utilized more paid services or other types of formal services than Black dementia CGs (Alzheimer's Association, 2021). Also, there is evidence the pandemic threatened social networks and limited face-to-face interactions more so for Black than White older adults (Gauthier et al., 2020). This may have led to

less family and support mobilization to aid in caregiving tasks and, therefore, more responsibilities fell on primary CGs (Gauthier et al., 2020).

Unanticipated, however, nearly the complete reverse was observed for IADL, such that White non-dementia CGs were most likely to provide *more* help with IADL and Black non-dementia CGs were most likely to provide *less* help with IADL. It is possible that Black PwD may have had lower baseline functioning, health, and health-related quality of life than Whites (Hayes-Larson et al., 2021; Moon et al., 2020) pre-pandemic, necessitating help with more basic ADL from Black dementia CGs. The rapid functional declines PwD may be experiencing during the pandemic (Borges-Machado et al., 2020; Goodman-Casanova et al., 2020; Simonetti et al., 2020) may explain why Black dementia CGs exhibited the most provision of help with ADL but not IADL.

These findings speak to the complexity of dementia CG responsibilities and how they are perceived, especially amidst an extraordinary global event. Similar to Cravello's (2021) findings regarding more dementia CG burden associated with CRs' declining ADL but not IADL function, we observed greater perceived care burden in all CGs with the provision of more help with ADL but not IADL. In contrast, Park's team (2018; 2015) found IADL but not ADL dependency to be a significant factor in explaining dementia care burden. Our unusual findings in direction of changes in assistance with ADL/IADL in Black dementia CGs—more provision of both ADL and IADL as well as less IADL help was associated with more burden—exemplify why generalizations about the perception of the burden from assisting PwD in daily activities, without consideration for race or type of caregiving task, may not be appropriate.

Emotional support provision also showed differences by race for dementia CGs. For White dementia CGs, providing CRs with emotional support during COVID-19 was significantly and positively related to both perceived care burden and psychological well-being and not associated with self-rated health. In contrast, for Black dementia CGs, doing so was significantly positively associated with self-rated health. These variations in perceived stressors may be explained by

cultural differences in Blacks' and Whites' views of caregiving. The value Black CGs place on their role, internal coping strategies, and cultural traditions that foster strong bonds among families (Badana et al., 2019; Skarupski et al., 2009) may have attenuated, for instance, the strain emotional support provision had on this CG group.

Quality of relationship to CRs was more consistent across dementia CGs. For Black dementia CGs, improved quality of relationship with the CR was associated with a lower level of perceived burden and better well-being and self-rated health. Somewhat similarly, White dementia CG experienced better well-being and self-rated health with improved relationship quality. The protective nature of having a close relationship with the CR, as found in previous studies (Pothiban et al., 2020; Rippon et al., 2020), applied regardless of race.

Several limitations of the current study should be noted. First, the sample was predominantly Whites. The unweighted sample size for White CGs was 1,024 (White dementia CGs n=216), but there were 205 Black CGs (Black dementia CGs n=59). Second, dementia care status is based on self-report, not clinical assessment or diagnosis. Third, we used the COVID-19 FF participants' help with ADL and IADL before the COVID-19 outbreak that occurred before the March 2020 outbreak, which can be less accurate than the current status of help. Fourth, the current study is cross-sectional, therefore precluding any causal inferences. Finally, due to small numbers (i.e., 65 respondents), we did not include any paid service utilization variable during COVID-19, and the available number of COVID FF participants (caregivers) per NHATS participant (range 1–2, 17 NHATS participants with two COVID FF participants).

Conclusion

Despite the limitations, our study underscores the importance of examining changes in CG stressors resulting from the COVID-19 pandemic through a nuanced lens—operationalizing differences both by absolute change and direction of change—as a means of better understanding

the complexity of differences in caregiving experiences for Black dementia CGs. Service providers and policy-makers should pay special attention to the distinctive context Black dementia CGs are facing during the outbreak, their particular caregiving responsibilities and how they are perceived, and their overall well-being. Future research should investigate the long-term negative and positive effects of ongoing care during COVID-19 on racially, ethnically, and geographically (e.g., urban, suburban, and rural settings) diverse CGs. Given the evidence of the variations in help with ADL and IADL tasks by race and dementia care status from our supplementary analyses, future studies should examine the impact of COVID-19 on the frequency and amount of caregiving and the association with CGs' well-being.

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Table 1. Proportions/Means of Demographic Characteristics and Study Variables by Race and Dementia Care Status (NHATS FF10, N=1,420, Weighted: 95% CI)

Variables	Total	Black		White	
		Dementia Care (n=56)	*Non-dementia Care (n=160)*	*Dementia Care (n=169)*	*Non-dementia Care (n=1035)*
CG Background Factors					
Age	62.3 (61.3–63.2)	57.0 (53.9–61.4)	58.5 (55.3–61.7)	63.5 (61.9–65.1)	62.4 (61.3–63.5)
Sex (Female)	.67 (.6–.7)	.85 (.7–.9)	.80 (.7–.9)	.67 (.6–.7)	.66 (.6–.7)
Education					
≥Some College	.80 (.7–.8)	.73 (.6–.8)	.62 (.5–.7)	.65 (.6–.7)	.80 (.7–.8)
Relationship to CR					
Spousal CG	.35 (.3–.4)	.15 (.1–.3)	.13 (.1–.2)	.24 (.2–.3)	.40 (.3–.4)
CG Stressors					
Help with Number of ADL before COVID-19	1.2 (1.1–1.3)	3.5 (2.8–4.2)	1.5 (1.2–2.0)	2.7 (2.4–3.1)	.9 (.7–1.0)
Help with Number of ADL during COVID-19	2.1 (2–2.2)	3.6 (2.8–4.4)	1.8 (1.4–2.2)	2.9 (2.5–3.3)	1.0 (.9–1.1)
Changes in Help with Number of ADL	.39 (.3–.5)	.64 (.4–.9)	.43 (.3–.6)	.79 (.6–1.0)	.29 (.2–.3)

Absolute Differences					
Direction of Differences					
Less Help with ADL during COVID-19	.08 (.06–.10)	.12(.06–.22)	.07 (.04–.12)	.14 (.1–.2)	.06 (.05–.08)
More Help with ADL during COVID-19	.18 (.1–.2)	.37(.3-.5)	.25 (.2–.3)	.24 (.2–.3)	.15 (.1–.2)
Help with Number of IADL before COVID-19	2.0 (1.9–2.1)	3.6 (2.5–3.1)	2.5 (2.3–2.8)	2.8 (2.5–3.1)	1.9 (1.8–2.0)
Help with Number of IADL during COVID-19	2.4 (2.3–2.5)	3.9 (3.5–4.4)	2.5 (2.0–3.0)	3.0 (2.7–3.4)	2.3 (2.1–2.4)
Changes in Help with Number of IADL					
Absolute Differences	.48 (.4–.5)	.51 (.05–.9)	.49 (.3–.6)	.42 (.3–.5)	.48 (.4–.5)
Direction of Differences					
Less Help with IADL during COVID-19	.07 (.5–.8)	.10 (.03–.15)	.15 (.1–.3)	.04 (.2–.8)	.06 (.04–.08)
More Help with IADL during COVID-19	.27 (.25–.30)	.19 (.1–.3)	.23 (.2–.3)	.23 (.2–.3)	.28 (.2–.3)
Emotional Support to CR during COVID-19	3.7 (3.6–3.8)	4.2 (3.8–4.5)	3.7 (3.6–4.0)	3.9 (3.8–4.1)	3.6 (3.5–3.7)
CG Coping Resource					
Relationship Quality with CR during COVID-19	11 (10.7–11.1)	9.8 (9.1–10.6)	12 (11.1–13.0)	9.8 (9.4–10.2)	11 (10.8–11.3)
CG Outcomes					
Perceived Care Burden during COVID-19	5.8 (5.6–5.9)	6.5 (5.8–7.2)	5.5 (5.2–5.9)	6.1 (5.8–6.4)	5.6 (5.3–5.8)

Psychological Well-being during COVID-19	11.1 (10.9–11.3)	10.8 (9.9–11.7)	11.5 (11–12.2)	10.9 (10.4–11.4)	11.1 (10.8–11.3)
Self-rated Health during COVID-19	3.7 (3.7–3.8)	3.4 (3.1–3.7)	3.4 (3.2–3.5)	3.6 (3.4–3.7)	3.8 (3.7–3.9)

Notes: Stressors= primary objective stressors; ADL =activities of daily living; CG = caregiver; CRs = care recipients; IADL = instrumental activities;

Proportions, means, and most CIs are rounded up to one decimal point

Table 2. Ordinary Least Squares Regressions of Caregivers' Perceived Care Burden, Psychological Well-being and Self-rated Health by Race and Dementia Care with Absolute Differences in ADL and IADL (NHATS FF 10, N=1,420, Weighted Sample)

Variables	Perceived Care Burden			Psychological Well-being			Self-rated Health		
	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3
CG Race (reference: White)									
Black	-.03[a]	-.13	-.17	.59*	.54*	.65*	-.37***	-.37***	-.40***
Dementia Care	.78***	.85***	.85***	-.27	-.17	-.12	-.16*	-.12	-.14
Race*Dementia Care			.10			-.45			.13
CG Background Factors									
Age	-.04***	-.04***	-.04***	.03***	.03***	.03***	-.01***	.01***	.01**
Gender (Female)	.16	.20	.20	-.32	-.36	-.035	.03	-05	.05
Education	.11	.11	.11	.03	.12	.12	.21***	.24***	.24****
Relationship to CR									
Spousal CG	.45**	.56**	.56**	.15	.08	.09	-.07	-.06	.44
CG Primary Objective Stressors									

	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3
Changes in Help with Number of ADL									
Absolute Differences		.04	.04		-.14	-.14		-.00	-.00
Changes in Help with Number of IADL									
Absolute Differences		.25*	.25*		-.27*	-.28*		-.30	-.03
Emotional Support to CR during COVID-19		.25***	.25***		.15	.14		-.05	-.04
CG Coping Resource									
Relationship Quality with CR during COVID-19		-.06	-.06		.11***	.11***		.00	.00
R^2	.07	.14	.14	.04	.07	.07	.12	.13	.13
F^b	8.2**	6.6***	6.1	10.0	6.4***	5.7***	26.0***	23.2***	25.4***

Notes: [s]Standardized coefficients are presented; [b]F values were rounded up to one decimal point.; ADL = activities of daily living; CRs = care recipients; IADL = instrumental activities of daily living; *p* < .05. **p* < .01. ***p* < .001. Model 1 adjusts for background factors. Model 2 adds stressors and a coping resource. Model 3 adds race*dementia care interaction effect.

Table 3. Ordinary Least Squares Regressions of Caregivers' Care Burden, Psychological Well-being and Self-rated Health by Race and Dementia Care with Direction of Differences in ADL and IADL (NHATS FF 10, N=1,420, Weighted Sample)

Variables	_Care Burden_			_Psychological Well-being_			_Self-rated Health_		
	Model 1	Model 2	Model3	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3
CG Race (reference: White)									
Black	-.03	-.08	-.20	.59*	.50*	.59	-.37***	-.33***	-.40***
Dementia care	.78***	.80***	.76***	-.26	-.22	-.17	-.16*	-.11	-.14
Race *Dementia care			.31			-.39			.20
CG Background Factors									
Age	-.04***	-.04***	-.04***	.04***	.03***	.03***	-.01***	.01***	.01**
Gender (Female)	.16	.15	.14	-.32	-.41*	-.40*	.03	.05	.05
Education	.11	.07	.08	.03	.10	.11	.21***	.22***	.22****
Relationship to CR									
Spousal CG	.45**	.50**	.43**	.15*	.07	.08	-.07	-.03	-.04
CG Primary Objective Stressors									
Changes in Help with Number of ADL									

Direction of Differences									
Less Help with ADL during COVID-19[1]		-.23	.23		-.75***	-.75***		-.11	-.11
More Help with ADL during COVID-19[1]		.37*	.37*		-.15	-.14		-.07	-.07
Changes in Help with Number of ADL									
Direction of Differences									
Less Help with IADL during COVID-19[2]		.16	.16		-.58	-.59		-.12	-.12
More Help with IADL during COVID-19[2]		.35	.36		-.63***	-.63***		.08	.08
Emotional support to CR during COVID-19[3]		.23.***	.23.***		.12	.12		-.04	-.04
CG Coping Resource									
Relationship Quality with CR during COVID-19		-.07*	-.07*		.11***	.13***		.00	.00
R^2	.07	.12	.12	.04	.07	.07	.12	.13	.13
F	6.7**	6.3***	5.8***	10.0	8.7***	7.8***	26.0***	14.0***	13.2***

Notes: Standardized coefficients are presented. ADL = activities of daily living; CRs = care recipients; IADL = instrumental activities of daily living; *p* < .05. **p* < .01. ***p* < .001; F values were rounded up to one decimal point. [1]The reference category is CGs, in which there was no difference in ADL before and during the outbreak; [2]The reference category is CGs, in which there was no difference in IADL before and during the outbreak; [3]Emotional support provided to CR before the COVID-19 outbreak was not asked. Model 1 adjusts for background factors. Model 2 adds stressors and a coping resource. Model 3 adds race*dementia care interaction effect.

Table 4. Ordinary Least Squares Regressions of Perceived Care Burden, Psychological Well-being and Self-rated Health among Black Dementia Caregivers (NHATS FF 10, N=56, Weighted Sample)

Variables	*Care Burden*		*Psychological Well-being*		*Self-Rated Health*	
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2
CG Primary Objective Stressors						
Changes in Help with Number of ADL						
Absolute Differences	.10		-.02		.01	
Direction of Differences						
Less help with ADL during COVID-19[1]		-1.5**		1.5		-.01
More help with ADL during COVID-19[1]		1.5*		-1.4**		.05
Changes in Help with Number of IADL						
Absolute Differences	.26*		2.8		-.30***	
Direction of Differences						
Less Help with IADL during COVID-19[2]		-1.9***		-1.2		-.46
More Help with IADL during COVID-19[2]		-1.6***		1.1		.09
Emotional support to CR during COVID-19[3]	.25	.-.13	.11	.05	.05	.03***

CG Coping Resource						
Relationship Quality with CR during COVID-19	-.10*	-.14	.11	.11*	.02	.01*
R^2	.10	.28	.10	.17	.19	.12
F	4.4	8.6***	3.2	21.6***	195.5**	5.8***

Notes: Standardized coefficients beta are presented. CRs = care recipients; *p* < .05, **p* < .01, ***p* < .001. We controlled for background factors; F values were rounded up to one decimal point. [1]The reference category is Caregivers, in which there was no difference in ADL before and during the outbreak; [2]The reference category is Caregivers, in which there was no difference in IADL before and during the outbreak; [3]Emotional support provided to CR before the COVID-19 outbreak was not asked. Model 1 includes absolute difference and Model 2 includes direction of difference.

Table 5. Ordinary Least Squares Regressions of Care Burden, Psychological Well-being and Self-rated Health among White Dementia Caregivers (NHATS FF 10, N=169, Weighted Sample)

Variables	Care Burden		Psychological Well-being		Self-rated Health	
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2
CG Primary Objective Stressors						
Changes in Help with Number of ADL						
Absolute Differences	-.00		-.20		-.03	
Direction of Differences						
Less Help with ADL during COVID-19[1]		-1.2***		-.78		-.02
More Help with ADL during COVID-19[1]		-.02		-.60		-.15
Changes in Help with Number of IADL						
Absolute Differences	.19		-.15		-.05	
Direction of Differences						
Less Help with IADL during COVID-19[2]		-.45		-.43		-.08
More Help with IADL during COVID-19[2]		.15		-.42		.16
Emotional support to CR during COVID[3]	.50***	.42***	.26*	.27**	.01	.02.
CG Coping Resource						

Relationship Quality with CR during COVID-19	-.06	-.02	.10**	.18***	.03*	.02
R^2	.15	.18	.06	.09	.16	.18
F	3.71**	4.78***	2.74*	1.76*	6.04***	5.56***

Notes: CRs = care recipients; Weighted data; Standardized coefficients are presented. We controlled for background factors. *p < .05. **p < .01. ***p < .001.; 1= The reference category is CGs, in which there was no difference in ADL before and during the outbreak; 2=The reference category is CGs, in which there was no difference in IADL before and during the outbreak.; 3= Emotional support provided to CR before the COVID-19 outbreak was not asked. Model 1 includes absolute difference and Model 2 includes direction of difference.