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Social Activity Restriction and Psychological Health Among Caregivers of Older Adults with and without Dementia

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Abstract

Objectives: We examined associations between social activity restriction and psychological distress and well-being for caregivers of older adults with and without dementia, and if the identified associations are different for the two groups.

Methods: Using data from the 2017 National Study of Caregiving, we identified caregivers of older adults with ($N=541$) and without ($N=1,701$) dementia. Linear regression models were estimated, adjusting for caregivers' age, gender, race, education, relationship to care recipient, and self-rated health.

Results: Restriction in visiting friends and family and attending religious services were associated with higher distress in dementia caregivers. Restriction in visiting friends and family was associated with higher distress and lower well-being in non-dementia caregivers. Any activity restriction had stronger association with distress for caregivers of older adults with vs. without dementia.

Discussion: Findings highlight the need for tailored interventions based on caregivers' perceptions of meaningful social activities and dementia-friendly communities to promote social participation.

Keywords: family caregivers, social participation, anxiety, depression, psychological well-being

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Introduction

In the United States (U.S.), more than 17.7 million people are providing assistance to an older adult family member or friend in the community (National Academies of Sciences & Medicine, 2016). Numerous studies have documented the social cost and psychological effects of caregiving. Caregivers of older adults report restriction in their social activities and substantial psychological distress due to their caregiving responsibilities. Certain subgroups of caregivers such as caregivers of older adults with dementia have different experiences than the broader population of caregivers. The purpose of this study is to examine the associations between social activity restrictions and psychological health among caregivers of older adults with and without dementia.

Caregiving and Psychological Health

Caregiving takes a heavy toll on caregivers' psychological health given the competing demands of caregiving and self-care that caregivers experience (Wang & Nguyen, 2023). In fact, family caregivers report worsening of psychological health after transitioning to a caregiving role (Haley et al., 2020). Psychological health includes two dimensions: psychological distress (i.e., symptoms of depression and anxiety) and psychological well-being (i.e., positive thoughts and feelings about one's life). Caregivers may experience negative emotions that are detrimental to their psychological health, such as feeling sad about the care recipient's deteriorating health and worrying about the future (Lee & Zurlo, 2014). Caregivers' role overload has been also linked to low levels of psychological well-being (Nah et al., 2022). Additionally, caregivers living with the care recipient and older spousal caregivers report lower levels of life satisfaction compared to non-caregivers (Barbosa et al., 2022; Lee et al., 2020). Given the adverse

psychological health effects of caregiving, it is imperative to examine modifiable contributors to psychological health to optimize caregivers' health and experiences.

Caregiving and Social Activity Restriction

Providing care on an ongoing basis to a family member or friend with a chronic illness or a disability can disrupt ones' engagement in valued social activities and caregivers are known to have more activity restriction compared to non-caregivers (Mausbach et al., 2008). Individuals who transition to a caregiving role report lower satisfaction with social activities and greater decline in social network size over time compared to non-caregivers (Liu et al., 2021). Given the well-established psychological health benefits of social participation, caregivers may be at risk for psychological distress (i.e., increased depressive and anxiety symptoms) due to social activity restriction. Sibalija et al. (2020) recently found that social participation is negatively associated with depressive symptoms among caregiver participants from the nationally representative Canadian Longitudinal Study on Aging. Furthermore, caregivers with higher levels of activity restriction experience greater depressive symptoms compared to caregivers and non-caregivers with less activity restriction (Loucks-Atkinson et al., 2006; Mausbach et al., 2008; Sibalija et al., 2020).

In terms of psychological well-being, studies suggest that social participation is positively associated with purpose in life and life satisfaction (AshaRani et al., 2022; Lee & Choi, 2020). However, there is limited evidence about those associations in the caregiving population. In a recent study, Barbosa et al. (2022) found that older spousal caregivers' social participation is positively associated with life satisfaction. Therefore, it is important to assess the contribution of social activity restriction to both psychological distress and well-being in order to identify intervention targets that address caregivers' psychological health as a whole.

Caregiving for Older Adults with and Without Dementia

Certain subgroups of caregivers are at higher risk of decreased social participation and psychological health than others. Caregivers of persons with dementia report greater decline in social network size and disruption to social activities compared to other caregivers (Liu et al., 2021; Meller, 2001). More specifically, Patterson et al. (2023) used data from the 2017 National Study of Caregiving to estimate social activity restrictions among caregivers for older adults with vs. without dementia, and evaluate whether caregiving hours contribute to the difference in activity restrictions between the two groups. They found that caregivers of older adults with dementia report twice as much social activity restriction compared to caregivers of older adults without dementia, and this marked difference can be partially attributed to greater caregiving hours for older adults with vs. without dementia. In fact, family caregivers of persons with dementia provide 3 times as many total hours of care over the last 10 years of life compared with caregivers of those without dementia (Reckrey et al., 2021).

Caregivers of persons with dementia provide constant monitoring to their loved ones and manage the unpredictable behavioral and psychological symptoms of dementia, which can lead caregivers to lose their sense of control over their personal lives and schedules (Kasper et al., 2015; Pearlin et al., 1990). The limitations imposed on one's personal activities and psychological health may be less significant when caring for older adults with other chronic conditions that are more predictable and require planned caregiving activities, compared to older adults with dementia. Besides the marked differences in caregiving intensity and social activity restrictions between caregivers of older adults with and without dementia, caregivers to older adults with dementia also experience worse psychological health compared to other caregivers (Sheehan et al., 2021). Caregivers of older adults with dementia provide more physical and medical assistance, which is more emotionally challenging than other activities, and socializing with the care recipient is emotionally challenging when the recipient has dementia (Freedman et al., 2022). Lei et al. (2023) recently found that increased impairment in self-care among older adults with dementia was associated with an increase in the probability of caregivers

reporting caregiving-related emotional difficulty, but this association was not significant among caregivers of older adults without dementia.

The prevalence of dementia is expected to continue to rise given the growing population of older adults who are at increased risk for dementia (Alzheimer's Association, 2022). Moreover, dementia is generally associated with higher costs and longer care duration compared to other chronic conditions, which has implications for caregivers providing ongoing support (Alzheimer's Association, 2022). Given the growing prevalence of dementia and significant implications on caregivers, there is a need to identify whether caregivers of older adults with vs. without dementia have different psychological health outcomes as a result of social activity restriction due to caregiving.

Theoretical Framework

According to the activity restriction model of depressed affect (Williamson & Shaffer, 2000), life stressors that result in restriction or disruption in usual pleasurable activities play a central role in the individual's psychological adjustment. Early testing of the model suggests that activity restriction is a potential explanation for how a health-related stressor (i.e., illness or disability) affects depressive symptoms. The authors propose that activity restriction should also predict other affective reactions that are prevalent in individuals experiencing stressful situation.

The activity restriction model was extended to include the distress associated with managing the health problem of a loved one as a precursor to activity restriction and poor psychological adjustment (Loucks-Atkinson et al., 2006; Williamson & Shaffer, 2000). Therefore, the model can be applied to the caregiving context and is well-aligned with the secondary role strain dimension of the Pearlin Stress Model (Pearlin et al., 1990). Caregivers often experience secondary stressors as a result of the needs of the care recipient and the nature and magnitude of the care demanded by these needs. An example of secondary role strain is "constriction of social life" which is then associated with poor mental health outcomes.

Purpose

Participation in social activities is associated with positive psychological health outcomes. Caregivers are at risk for social activity restrictions, which would further negatively influence their psychological health. The existing literature is primarily derived from non-nationally representative samples of caregivers in the U.S. and from samples of caregivers residing in other countries whose caregiving and social participation experiences may not be comparable to caregivers in the U.S. In fact, Yen et al. (2022) reported differences in social participation across 30 countries, which may be attributed to cultural variation or differences in social and economic resource availability. Additionally, it remains unclear if overall social activity restriction, or only restriction in certain social activities, contribute to psychological health among caregivers, and if the identified associations are different for caregivers of older adults with and without dementia. Using data from the National Study of Caregiving (NSOC), a nationally representative study of caregivers in the U.S., we examined how overall social activity restriction, and restriction in specific social activities, contribute to psychological health (i.e., distress and well-being) among caregivers of older adults with and without dementia. We hypothesized that higher levels of social activity restriction are associated with poor psychological health (i.e., high distress and low well-being) for caregivers of older adults with and without dementia, and that the associations are stronger for caregivers of older adults with vs. without dementia.

Methods

Data Source and Sample

This study used a cross-sectional research design. Data were drawn from the 2017 wave of the National Study of Caregiving (NSOC), which included family and unpaid caregivers of participants in the 2017 National Health Aging Trend Study (NHATS)—a nationally representative study of Medicare beneficiaries aged 65 and older. Eligibility for participation in the NSOC study was determined using a two-stage screening process. At Stage 1, Sample Persons were selected from NHATS if they were

receiving help with mobility activities, self-care activities, or household activities for health or functioning-related reasons in the last month. Then, eligible Sample Persons were asked to identify all caregivers who assisted them with the abovementioned activities. At Stage 2, caregivers who met the following criteria were eligible to participate in the NSOC: (1) provided assistance to an NHATS Sample Person with mobility, self-care, household or other activities (e.g., physician visits) and (2) were either related to the Sample Person whether paid or not, or unrelated to the Sample Person and not paid to help. Eligible NSOC participants completed a 30-minute telephone interview and answered questions about their experiences including care activities, duration and intensity of care, interactions with healthcare providers, availability of support, effects of caregiving on well-being, and demographic information. Screening and data collection procedures were described in detail in the NSOC I-III User Guide Version 5.0 (Freedman et al., 2019).

For the current analysis, we included NSOC participants who provided care in the last month before data collection to a living NHATS participant ($N = 2,242$). We split our sample of caregivers based on whether the care recipient had dementia. Dementia status classification was based on three sources of NHATS data (depending on data availability): (a) NHATS participant or proxy respondent report that a doctor ever told the NHATS participant that he/she had dementia or Alzheimer's disease; (b) proxy responses on the AD8 dementia screening interview (Galvin et al., 2005); or (c) NHATS participant scores at or below 1.5 SDs from the mean in at least two of the three cognitive domains (memory, orientation, and executive function) assessed by NHATS' series of cognitive tests. We followed the criteria of dementia screening and the technical process of classifying dementia status used in previous studies (Kasper et al., 2013; Skehan & Spillman, 2013) and generated a dementia status variable using NHATS data with three categories (i.e., possible dementia, probable dementia, and no dementia). We adopted the narrow definition of dementia, as recommended by Kasper et al. (2013), and recoded probable dementia as 1 "dementia," and possible dementia and no dementia as 0 "no dementia." Based on the

NHATS Sample Person's dementia status, we constructed a Dementia Caregiver group ($N = 541$) and a Non-Dementia Caregiver group ($N = 1,701$).

Measures

Psychological Health.

Psychological distress was measured using the Patient Health Questionnaire (PHQ)-4 (Kroenke et al., 2009). Participants reported on the frequency of experiencing depression and anxiety symptoms on a 4-point Likert scale (1 = *not at all* to 4 = *nearly every day*). The following symptoms were assessed: (1) little interest or pleasure in doing things; (2) feeling down, depressed, or hopeless; (3) feeling nervous, anxious, or on edge; and (4) unable to stop or control worrying. Summary scores were calculated with higher scores indicating higher levels of psychological distress. The Cronbach's alpha of psychological distress in the current study sample was 0.77, indicating acceptable reliability (Cortina, 1993).

Psychological well-being was measured using 3 items from the Ryff Scales of Psychological Well-Being (Ryff, 1989). Participants reported on their agreement with the following statements: "My life has meaning and purpose," "I feel confident and good about myself," "I like my living situation very much." Responses were recorded on a 4-point Likert scale (1 = *agree strongly* to 4 = *disagree strongly*). All items were reverse-coded and sum scores calculated, with higher scores reflecting higher levels of psychological well-being. The Cronbach's alpha of psychological well-being in the current sample was 0.60.

Social Activity Restriction.

Social activity restrictions refer to activities reported as being somewhat or very important to the caregiver that were limited in the prior month because of caregiving. Social activities included: visiting friends and family, attending religious services, attending club meetings or group activities, and going out for enjoyment. We followed the steps recommended in prior research (Fabius et al., 2020;

Wolff et al., 2016) to create four separate variables that represent restriction in each of the four social activities (0 = no restriction, 1 = activity restriction). First, caregivers reported on the social activities that they participated in during the past month by responding to separate questions about each social activity (i.e., “in the past month, did you [do this activity]?”). Then, they indicated whether they were unable to participate in the activity due to caregiving (i.e., “in the last month, did helping [your loved one] ever keep you from [doing this activity]?”). Last, they rated the relative importance of each activity (1 = *very important*, 2 = *somewhat important*, and 3 = *not so important*). Caregivers were characterized as having participation restriction in an activity if the activity was somewhat or very important, and they were unable to participate because of providing care. We also created a composite variable to indicate whether caregivers had restriction in any social activity (0 = *no restriction*, 1 = *restriction in any social activity*).

Covariates.

Covariates included caregivers’ sociodemographic characteristics, relationship to care recipient, and general health perception. We selected covariates based on our review of the literature and prior investigations that used the Activity Restriction Model as a guiding framework (Loucks-Atkinson et al., 2006; Sibalija et al., 2020). We controlled for age (in years), gender (0 = *male*, 1 = *female* [sic]), education (0 = *high school or below*; 1 = *some college or Associate’s degree*; 2 = *Bachelor’s degree*; 3 = *Master’s, professional, or doctoral degree*), race (0 = *non-White*, 1 = *White*). The non-White category included African Americans, Indian Alaska Natives, Asians, and Native Hawaiian Pacific Islanders. We controlled for caregivers’ relationship to the care recipients (0 = *nonrelative*, 1 = *spouse*, 2 = *other relative*, 3 = *adult child*). Last, we controlled for caregivers’ self-rated health, which was assessed using a single-item measure (1 = *excellent* to 5 = *poor*) that was reverse coded, with higher scores reflecting better self-rated health.

Caregiving intensity, measured using assistance with activities of daily living and instrumental activities of daily living, was tested as a covariate during model building but was removed in the final analyses due to its statistical nonsignificance across all models and because its addition did not change the coefficients of the other predictors. Similarly, caregiving hours was initially tested as a covariate but removed from the final models to maintain parsimony because its addition did not alter the results in any way.

Statistical Analysis

All analyses were conducted using STATA 17.0. First, descriptive statistics were used to summarize the sample characteristics and study variables. Bivariate analyses (i.e., Chi-square tests, independent t tests) were used to identify significant differences in the sample characteristics and study variables between the dementia and non-dementia caregiver groups. Then, we ran separate linear regression models with survey sampling weights to provide nationally representative estimates of the associations between social activity restriction and psychological health (i.e., distress and well-being). One set of models (Models 1 and 2) included the composite variable of activity restriction to represent restriction in any social activity. The other set of models (Models 3 and 4) included the four variables about specific social activities that were restricted due to caregiving. Separate models were estimated for each outcome of interest (i.e., distress and well-being) among caregivers of older adults with and without dementia. All models were adjusted for caregivers' age, gender, race, education level, relationship to care recipient, and self-rated health. Last, a series of Wald tests (Klopp, 2020) were conducted to compare the significant effects of activity restriction on psychological health between the caregiving group. A Wald score was calculated based on the unstandardized coefficients (B_1 , B_2) and standard errors (SE_1 , SE_2) of activity restriction variables in each group. The mean of the Wald score was then computed on the full sample. If the mean is greater than 1.96 ($p < .05$ on a z-distribution), the magnitudes of the association between activity restriction and psychological health in the dementia and

non-dementia caregiver groups are significantly different. When significant differences were identified, we examined effect sizes to determine which group had stronger associations between activity restriction and psychological health. Given that some NHATS participants have more than one caregiver enrolled in NSOC, we randomly selected one caregiver for each NHATS participant to conduct a sensitivity analysis. We ran the same set of models (models 1-4) using the random sample to check whether non-independence affected our results. To remain consistent with prior studies using NSOC, we opted to use all cases in the main analysis and presented the results of the randomly selected sample as a sensitivity analysis.

Results

Sample Characteristics and Description of Study Variables

Caregiver participants were on average 61.61 (± 14.27) years old. Most participants were women (67.48%), White (67.53%), and had at least some college education or a college degree (64.23%). Over half (55.08%) provided care to their parents. On average, participants reported relatively low levels of psychological distress, moderate levels of self-rated health, and moderate-to-high levels of psychological well-being.

Table 1 includes a summary and comparison of sample characteristics and social activity restriction between the dementia and the non-dementia caregiver group. The bivariate analyses indicated differences in sociodemographic characteristics, social activity restriction, and self-rated health. More people of color provided care to an older adult with dementia than those who provided care to an older adult without dementia ($\chi^2 = 13.75, p < .001$). There were more adult children in the dementia caregiver group than the non-dementia caregiver group ($\chi^2 = 35.84, p < .001$). Additionally, there were more caregivers of older adults with dementia reporting restriction in any social activity, compared to caregivers of older adults without dementia ($\chi^2 = 41.18, p < .001$). Across all activity restriction variables, the percentage of caregivers with restriction to any social activity was almost 1.5 to

2 times as large among caregivers of older adults with dementia, when compared to caregivers of older adults without dementia. Last, caregivers of older adults with dementia had poorer self-rated health compared to caregivers of older adults without dementia ($t = 2.82, p < .01$). We first present the results of our main analysis using the full sample that includes one or more caregivers for each NHATS participant.

Restriction in any Social Activity and Psychological Health

First, we examined the association between any social activity restriction and psychological distress and well-being among caregivers of older adults with (Model 1) and without dementia (Model 2). Consistent with our hypothesis, restriction in any social activity was positively associated with psychological distress and negatively associated with psychological well-being in both groups, while adjusting for caregivers' age, gender, race, education level, relationship to care recipient, and self-rated health (see Table 2).

Restriction in Specific Social Activities and Psychological Health

Next, we examined the association between activity restriction in specific social activities and psychological distress and well-being among caregivers of older adults with (Model 3) and without dementia (Model 4), while adjusting for the same covariates as in the first set of models (see Table 3). For caregivers of older adults with dementia, being restricted in visiting friends and family and attending religious services were associated with higher levels of psychological distress ($B = 0.91, p = 0.029$ and $B = 1.93, p < 0.001$, respectively). As for caregivers of older adults without dementia, restriction in visiting friends and family was associated with higher levels of psychological distress ($B = 0.65, p = 0.014$) and lower levels of psychological well-being ($B = -0.37, p = 0.038$). All regression models (models 1-4) were also estimated with additional covariates for caregiving intensity (i.e., ADL/IADL assistance or hours of care), but the results remained unchanged (models not shown).

Comparison of Significant Effects for Caregivers of Older Adults with and Without Dementia

Last, we used the Wald test to compare the significant effects of activity restriction on psychological health for caregivers of older adults with and without dementia. Our second hypothesis was partially supported. We found a significant between-group difference in the association between any activity restriction and psychological distress ($M_{\text{wald score}} = 3.47$). Upon comparing the regression coefficients for the two groups, we found that restriction in any social activity had a stronger association with psychological distress for caregivers of older adults with dementia, compared to caregivers of older adults without dementia. We did not find statistically significant differences between the two caregiving groups for the association between any activity restriction and psychological well-being ($M_{\text{wald score}} = 0.54$) and the association between restriction in visiting friends and family and psychological distress ($M_{\text{wald score}} = 0.54$).

Sensitivity Analysis

The sensitivity analysis using the randomly selected sample of caregivers resulted in comparable results to our main analyses. Restriction in any social activity was positively associated with psychological distress and negatively associated with psychological well-being among both groups of caregivers (see Supplementary Table S1). The significant association between any activity restriction and psychological distress was stronger for caregivers of older adults with dementia, compared to caregivers of older adults without dementia ($M_{\text{wald score}} = 2.85$).

For caregivers of older adults with dementia, being restricted in visiting friends and family and attending religious services were associated with higher levels of psychological distress and lower levels of psychological well-being (see Supplementary Table S2). As for caregivers of older adults without dementia, restriction in visiting friends and family was associated with higher levels of psychological distress, and restriction in going out for enjoyment was associated with lower levels of psychological well-being (see Supplementary Table S2). The magnitudes of the significant associations between

restriction in specific activities and psychological health were not different for the two caregiving groups.

Discussion

The purpose of this study was to examine how social activity restriction contributes to psychological health (i.e., distress and well-being) among caregivers of older adults with and without dementia. First, we found that restriction in any social activity was positively associated with psychological distress and negatively associated with psychological well-being in both caregiving groups. Second, when examining restriction in specific social activities, we found that among caregivers of older adults with dementia, being restricted in visiting friends and family and attending religious services were associated with higher levels of psychological distress. As for caregivers of older adults without dementia, restriction in visiting friends and family was associated with higher levels of psychological distress and lower levels of psychological well-being. Last, we identified a difference in the magnitudes of the association between any activity restriction and psychological health for the two caregiving groups, with any activity restriction having a stronger association with psychological distress for caregivers of older adults with dementia, compared to caregivers of older adults without dementia. Our findings have implications for tailoring interventions to promote social participation among caregivers of older adults.

Restriction in social activities was associated with psychological distress and well-being for caregivers of older adults with and without dementia. Our findings are consistent with findings from previous studies (Loucks-Atkinson et al., 2006; Mausbach et al., 2008; Sibalija et al., 2020), but extend knowledge of the implications of social activity restrictions to representative caregiving samples of older adults in the U.S. Additionally, the restriction variable used in the current study was created by accounting for restrictions in meaningful social activities due to caregiving. Therefore, the findings also consider the importance of the social activity to the caregiver, and their perceived caregiving intensity

that prevents them from social participation. Social participation is an avenue to connect with others, exchange ideas, and receive support. When caregivers are unable to engage in meaningful social activities due to their caregiving role, their perception of control over their personal independence and other important aspects of their life becomes threatened, therefore influencing their overall well-being.

We found that restriction in visiting friends and family was positively associated with psychological distress and negatively associated with psychological well-being in both caregiving groups, which is in line with the extensive literature about social interactions and psychological health. Visiting friends and family provides caregivers with the opportunity to receive emotional support and enhance their psychological health. It may also provide an opportunity to receive respite care; respite care through adult day programs and subjective respite (i.e., caregivers' perception of getting a break from caregiving responsibilities) are known to decrease caregivers' levels of psychological distress (Bangerter et al., 2021; Wylie et al., 2021).

Restriction in attending religious services was a significant predictor of psychological distress for caregivers of older adults with dementia. Our finding is consistent with a previous study that found inverse associations between the frequency of attendance at religious services, meetings, and/or activities and depressive symptoms among caregivers of persons with Alzheimer's disease who participated in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study (Hebert et al., 2007). Religious participation is an important resource, specifically in racial and ethnic minority populations because it promotes healthy behaviors, stress-management strategies, and positive relationships and support within the congregational network (Nguyen, 2020). Our finding about restriction in attending religious services is specific to the dementia caregiver group, which also included a higher proportion of non-White caregivers compared to the non-dementia caregiver group. Therefore, the difference in predictors for psychological distress between the two groups may be attributed to the group of dementia caregivers having a higher proportion of non-White caregivers who may value

religious coping. Additional research is needed to examine whether the differences between the two groups can be explained by the caregiver's racial identity.

In a recent study using data from the NSOC, Patterson et al. (2023) found that restrictions in meaningful social activities are more prevalent among caregivers of older adults with dementia, compared to other caregivers. Our findings build on this emerging literature and highlight differences in the psychological health repercussions of social activity restriction in the two caregiving groups (caregivers of older adults with vs. without dementia). Despite accounting for caregiving intensity (i.e., ADL/IADL assistance and/or hours of care; models not shown), our results were unchanged. This suggests that our primary predictor variable (social activity restriction) accounts for any differences in associations that we might observe between the two groups of caregivers related to caregiving intensity. High levels of caregiving intensity are associated with poor psychological health (Kolodziej et al., 2022; Schulz et al., 2020) and caregiving intensity (i.e., caregiving hours) partially explains differences in social activity restriction for caregivers of older adults with vs. without dementia (Patterson et al., 2023). Future research is needed to evaluate the potential pathway of caregiving intensity that explains our established differences in the psychological health repercussions of social activity restriction between the two caregiving groups.

The findings have important research, practice, and policy implications. Insights gained from this study can inform intervention development for caregivers at risk for social activity restriction. Interventions can be designed to increase participation in meaningful activities, even in the presence of caregiving responsibilities. As recommended in a recent call to promote social connection in dementia caregivers, including the voice of caregivers is essential to elicit their preferences and priorities (Van Orden & Heffner, 2022). Tailored interventions are needed based on caregivers' perceptions of meaningful social activities. Caregivers would be asked which aspects of social participation are most meaningful to them to guide the development of personalized approaches that address social activity

restriction. Future research is needed to explore the use of videoconferencing and other technologies to facilitate social participation especially among caregivers of persons with dementia and evaluate if such approaches would mitigate psychological distress.

In terms of practice implications, clinicians and other community workers should assess how caregiving responsibilities influence caregivers' ability to maintain meaningful social activities and identify caregivers who would benefit from interventions emphasizing caregiving support through formal and informal networks that may allow caregivers the flexibility to be more socially engaged if they would like. Last, based on our bivariate and multivariate analyses, caregivers of older adults with dementia have more social activity restriction and the effect of their activity restriction on psychological distress is stronger compared to non-dementia caregivers. Therefore, our findings have policy implications for creating and expanding dementia-friendly communities to promote social participation (Hung et al., 2021).

Our findings should be interpreted considering several important limitations. First, we used a cross-sectional study design and cannot examine causal inferences between social activity restriction and psychological health. Caregivers with psychological distress may not be able to participate in social activities and may not consider some kinds of social activities as important. Moreover, the available data are based on caregivers' self-report of activities restricted in the past month. Caregivers may have experienced activity restriction in some capacity prior to the month-period of data collection, and that would not be captured in this study. Second, the NSOC does not include data from non-caregiver participants, which limits our ability to draw definite conclusions about the psychological health implications of social activity restriction due to caregiving. Third, despite using data from a nationally representative sample of caregivers, we were limited in our subgroup analyses due to the limited number of caregivers in each racial and gender subgroups who reported restriction in specific social activities. Additionally, our results may not be generalizable to caregiver of older adults from other

countries. Fourth, there may be other variables that help us explain the associations established in this study. For instance, caregivers who utilize formal support services may be less affected by social activity restriction, compared to those who do not utilize formal support services. The activity restriction model suggests that relationship quality may play a role in how activity restriction is related to psychological health (Williamson & Shaffer, 2000). Caregivers experiencing poor relationship quality with the care recipient may be more vulnerable to psychological distress from restriction in social activities as compared to those reporting positive relationships. Caregivers with poor relationship quality may perceive their care recipient as source of “interference” by preventing them from engaging in social activities, and thus experience stronger negative emotions in response (Knobloch et al., 2020). Future research is needed to examine the role of formal support and relationship quality in the relationship between social activity restriction and psychological health. Additionally, there are likely other psychosocially significant caregiver traits that were not available in the NSOC such as emotion regulation and personality type, which may lead a caregiver to be at greater risk of regret for missing out on social participation, compared to those who perhaps are less likely to seek social participation. Last, we used data collected well before the COVID-19 pandemic. There were many social disruptions and changes since the start of the pandemic that may have influenced caregivers’ priorities for social participation. Despite these limitations, our findings highlight the psychological health consequences of social activity restriction and inform future investigations about potential modifiable factors to promote psychological health of caregivers who are at risk for social activity restriction.

In conclusion, social activity restriction is associated with psychological distress and well-being among caregivers of older adults with and without dementia. More specifically, restrictions in visiting friends and family and attending religious services were associated with psychological distress among caregivers of older adults with dementia, while restrictions in visiting friends and family were associated with psychological distress and well-being among caregivers of older adults without dementia. Overall,

caregivers of older adults with dementia experience stronger psychological repercussions from social activity restriction, compared to caregivers of older adults without dementia. Tailored interventions that consider caregivers' responsibilities and perceptions of meaningful social activities can optimize caregivers' psychological health and potentially improve the quality of care they provide to older adults.

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Tables

Table 1: Sample Characteristics and Key Study Variables for Caregivers of Older Adults with and Without Dementia

	Dementia Caregivers (<i>n</i> = 541)	Non-Dementia Caregivers (<i>n</i> = 1,701)	Test
Age (in years)	61.77 ± 13.69	61.44 ± 14.63	<i>t</i> = -0.45
Gender			$\chi^2 = 0.69$
Male	168 (31.05)	561 (32.98)	
Female	373 (68.95)	1140 (67.02)	
Race			$\chi^2 = 13.75^{***}$
Non-White	197 (39.24)	493 (30.38)	
White	305 (60.76)	1130 (69.62)	
Education			$\chi^2 = 5.15$
High school or below	197 (37.60)	580 (35.19)	
Some college	189 (36.07)	559 (33.92)	
Bachelor's degree	84 (16.03)	282 (17.11)	
Master's degree or above	54 (10.31)	227 (13.77)	
Caregiver-care recipient relationship			$\chi^2 = 35.84^{***}$
Nonrelative	31 (5.73)	128 (7.52)	
Spouse	73 (13.49)	403 (23.69)	
Other relatives	84 (15.53)	288 (16.93)	
Adult children	353 (65.25)	882 (51.85)	
Visiting restriction			$\chi^2 = 23.37^{***}$
No	425 (79.74)	1489 (88.05)	
Yes	108 (20.26)	202 (11.95)	
Religious service restriction			$\chi^2 = 20.82^{***}$
No	469 (87.83)	1583 (93.84)	
Yes	65 (12.17)	104 (6.16)	
Group activity restriction			$\chi^2 = 20.27^{***}$
No	474 (88.76)	1596 (94.44)	
Yes	60 (11.24)	94 (5.56)	
Going out restriction			$\chi^2 = 16.14^{***}$
No	452 (84.96)	1538 (91.06)	

Yes	80 (15.04)	151 (8.94)	
Restriction in any activity			$\chi^2 = 41.18^{***}$
No	366 (68.93)	1,382 (81.97)	
Yes	165 (31.07)	304 (18.03)	
Self-rated health (range 1-5)	3.35 ± 1.04	3.49 ± 1.05	$t = 2.82^{**}$
Psychological distress (range 4-16)	6.17 ± 2.68	5.96 ± 2.37	$t = -1.75$
Psychological well-being (range 3-12)	10.92 ± 1.51	10.94 ± 1.50	$t = 0.30$

Note. Percentages (presented within parentheses) and *n* are presented for categorical variables. Means and Standard Deviations (presented within parentheses) are presented for continuous variables.

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

Table 2: Restriction in any Social Activity and Psychological Health for Caregivers of Older Adults with and Without Dementia

	Dementia Caregivers (Model 1)				Non-Dementia Caregivers (Model 2)			
	Psychological distress		Psychological well-being		Psychological distress		Psychological well-being	
	<i>B (SE)</i>	<i>p</i>	<i>B (SE)</i>	<i>p</i>	<i>B (SE)</i>	<i>p</i>	<i>B (SE)</i>	<i>p</i>
Restriction in any Social Activity	1.68 (0.25)	<0.001	-0.69 (0.21)	0.002	0.61 (0.19)	0.002	-0.55 (0.14)	<0.001

Note. *B* = unstandardized estimate; *SE* = standard error. Models adjusted for caregiver's age, gender, race, education level, relationship to care recipient, and self-rated health.

Table 3: Restriction in Specific Social Activities and Psychological Health for Caregivers of Older Adults with and Without Dementia

	Dementia Caregivers (Model 3)				Non-Dementia Caregivers (Model 4)			
	Psychological distress		Psychological well-being		Psychological distress		Psychological well-being	
	<i>B (SE)</i>	<i>p</i>	<i>B (SE)</i>	<i>p</i>	<i>B (SE)</i>	<i>p</i>	<i>B (SE)</i>	<i>p</i>
Visiting Restriction	0.91 (0.41)	.029	-0.47 (0.24)	.058	0.65 (0.26)	.014	-0.37 (0.17)	.038
Religious service restriction	1.93 (0.44)	<.001	-0.28 (0.25)	.273	-0.25 (0.27)	.372	-0.21 (0.23)	.368
Group activity restriction	0.93 (0.57)	.107	0.07 (0.36)	.857	0.30 (0.30)	.329	-0.30 (0.21)	.157
Going out restriction	0.03 (0.35)	.924	-0.55 (0.34)	.110	0.34 (0.33)	.317	-0.39 (0.20)	.051

Note. *B* = unstandardized estimate; *SE* = standard error. Models adjusted for caregiver's age, gender, race, education level, relationship to care recipient, and self-rated health.

Supplementary Table S1: Restriction in any Social Activity and Psychological Health for a Random Sample of Caregivers of Older Adults with and Without Dementia

	Dementia Caregivers (Model S1)				Non-Dementia Caregivers (Model S2)			
	Psychological distress (<i>n</i> = 280)		Psychological well-being (<i>n</i> = 286)		Psychological distress (<i>n</i> = 976)		Psychological well-being (<i>n</i> = 993)	
	<i>B</i> (<i>SE</i>)	<i>p</i>	<i>B</i> (<i>SE</i>)	<i>p</i>	<i>B</i> (<i>SE</i>)	<i>p</i>	<i>B</i> (<i>SE</i>)	<i>p</i>
Restriction in any Social Activity	2.03 (0.37)	<0.001	-0.77 (0.26)	0.005	0.78 (0.23)	0.001	-0.68 (0.16)	<0.001

Note. *B* = unstandardized estimate; *SE* = standard error. Models adjusted for caregiver's age, gender, race, education level, relationship to care recipient, and self-rated health.

Supplementary Table S2: Restriction in Specific Social Activities and Psychological Health for a Random Sample of Caregivers of Older Adults with and Without Dementia

	Dementia Caregivers (Model S3)				Non-Dementia Caregivers (Model S4)			
	Psychological distress		Psychological well-being		Psychological distress		Psychological well-being	
	<i>B (SE)</i>	<i>p</i>	<i>B (SE)</i>	<i>p</i>	<i>B (SE)</i>	<i>p</i>	<i>B (SE)</i>	<i>p</i>
Visiting Restriction	1.24 (0.58)	0.039	-0.91	0.013	0.68 (0.32)	0.040	-0.24 (0.19)	0.206
Religious service restriction	2.34 (0.56)	<0.001	-0.68	0.006	-0.30 (0.41)	0.472	-0.39 (0.30)	0.200
Group activity restriction	0.80 (0.63)	0.210	0.31	0.240	0.12 (0.43)	0.787	0.10 (0.25)	0.703
Going out restriction	-0.29 (0.58)	0.616	-0.18	0.579	0.56 (0.46)	0.234	-0.76 (0.24)	0.002

Note. *B* = unstandardized estimate; *SE* = standard error. Models adjusted for caregiver's age, gender, race, education level, relationship to care recipient, and self-rated health.