

RESEARCH ARTICLE

COVID-19 pandemic experiences of older adults with dementia in community and residential care settings: Results from a US national survey

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Abstract

Introduction: Investigations into consequences of the US COVID-19 pandemic for older adults with dementia have been limited.

Methods: We used the National Health and Aging Trends Study to examine self-reported COVID-19 infection; measures taken to limit its spread; social, behavioral, and emotional responses to the pandemic; and changes in health-care use and provider communication. We compared adults aged ≥ 70 with and without dementia in community and residential care settings.

Results: In residential care settings, infection was substantially higher and social contact less common for those with dementia. In community and residential care settings, those with dementia had 2 to 3 times the odds of reporting sleeping more often. In residential care settings, those with dementia were less likely to put off care and more likely to start telehealth.

Discussion: Findings highlight the disproportionate social and behavioral consequences of the COVID-19 pandemic for those living with dementia, particularly in residential care settings.

KEYWORDS

community and residential care settings, COVID-19 infection and dementia, health-care use, pandemic mitigating behaviors, responses to the pandemic

HIGHLIGHTS

- Data are from the nationally representative National Health and Aging Trends Study.
- COVID-19 infection was higher in residential care settings for those with dementia.
- Social contact was less common for those with dementia in residential care.
- Pandemic-related coping behaviors differed by dementia and residential status.
- In residential care, those with dementia were less likely to delay health care.

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1 | INTRODUCTION

The first wave of the coronavirus disease 2019 (COVID-19) pandemic brought sweeping changes to the lives of older adults. In the United States, high risk of severe COVID-19 led many older adults to adopt behaviors to limit its spread, including staying at home;¹ reducing social contact with non-resident family and friends;² and adopting related behavioral changes such as hand washing, masking, and physical distancing.^{3,4} Other studies suggest increased reports of psychosocial distress among older adults during this time,⁵⁻⁷ as well as declines in physical activity.⁸ Changes in health-care delivery were also observed as older adults delayed care and turned to telehealth visits.^{9,10}

Older adults living with dementia face unique circumstances that may both impede the ability to avoid COVID-19 infection and exacerbate negative outcomes related to pandemic mitigation guidelines.¹¹ Yet, nationally representative investigations into the consequences of the pandemic for older adults with dementia have been limited. One national study in the United States found that during the first wave of the pandemic, older adults with dementia and milder forms of cognitive impairment had a higher risk of contracting COVID-19 than older adults without cognitive impairment and were less likely to engage in some mitigation behaviors such as hand washing.⁴ Other research has drawn attention to the distinctive needs of older adults in residential care settings,¹² which serve a disproportionate share of those living with dementia in the United States.¹³⁻¹⁵ One national study found acute levels of loneliness in residential care settings that were linked to facility-imposed limitations on visitors and group activities.¹⁶ Yet, investigations into differences in pandemic experiences for those with and without dementia by residential setting—community versus residential care such as nursing homes or assisted or independent living facilities—are lacking.

This study characterizes the COVID-19 pandemic experiences of older adults with and without dementia in community and residential care settings in the United States during the summer of 2020. We use data from the nationally representative National Health and Aging Trends Study (NHATS) to examine self-reported COVID-19 infection; measures taken to limit the spread of COVID-19; social, behavioral, and emotional responses to the pandemic; and changes in health-care use and communication with providers during the pandemic. We hypothesize that older adults living with dementia in both community and residential care settings were less likely to engage in mitigation behaviors and more likely to experience: COVID-19 infection; negative social, behavioral, and emotional responses; delays in health-care use; and less uptake of telehealth visits than older adults without dementia, and that these gaps were likely to be larger in residential care settings than community settings.

2 | METHODS

Data for this analysis are from the National Health and Aging Trends Study (NHATS), an ongoing national panel study of Medicare enrollees aged 65 and older living in the United States. Participants were

RESEARCH IN CONTEXT

- 1. Systematic Review:** The authors reviewed the literature using traditional online sources (e.g., PubMed, Centers for Disease Control website, American Geriatrics Society). To date, there have been several publications describing the consequences of the COVID-19 pandemic for older adults with dementia. These publications are appropriately cited.
- 2. Interpretation:** Our findings suggest differential pandemic experiences by dementia status for older adults. This hypothesis is consistent with findings currently in the public domain. We add to these findings by highlighting important key differences by residential status (e.g., community dwelling vs. residential care).
- 3. Future Directions:** Strategies are needed to mitigate the spread of COVID-19 that stop short of avoiding contact altogether to attenuate the disproportionate social and behavioral consequences of the pandemic for those living with dementia.

recruited into the NHATS sample in either 2011 (study initiation) or 2015 (replenishment). Annual interviews are conducted with study participants; cases who are not able to answer for themselves (typically 7%–8%) complete their interview with a knowledgeable proxy.¹⁷ In 2020, the minimum age of the NHATS sample was 70 years. Human subject procedures for NHATS were approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board and all participants provided written informed consent.

In 2020, NHATS participants who completed a Round 10 phone interview (response rate 96%) were eligible to complete a supplemental COVID-19 mail study (response rate 82%) about their pandemic experiences.¹⁸ Most booklets were completed in July and August 2020. This study draws upon data from the 3257 participants, aged 70 and older, who completed their COVID-19 booklet during 2020 data collection (Figure 1). Of the completed booklets, 2728 were completed independently, 107 were completed by the NHATS participant with assistance from another person, and 422 were completed by a proxy respondent. Of the completed booklets, 3007 were completed by participants residing in the community and 250 were completed by participants living in a residential care setting. Facilities offering food services or medication management were classified as residential settings, and included independent living, assisted living, and nursing home settings.

2.1 | Dementia measure

Using responses to the 2020 NHATS interview, we classified each participant as having probable dementia (hereafter, “dementia”; $N = 377$) or not ($N = 2880$). Individuals were classified as having dementia if

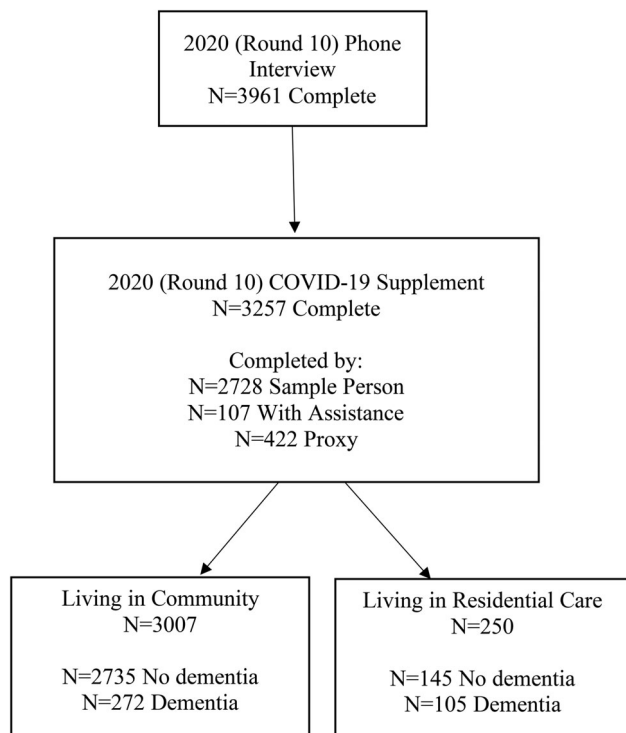


FIGURE 1 Analytic sample from the National Health and Aging Trends Study 2020 COVID-19 supplement

they met the following criteria: (1) the participant or a proxy respondent reported that a doctor had ever told the participant that he/she had dementia or Alzheimer's disease; (2) a proxy gave responses to an eight-item AD8 screener that met the likely dementia threshold (a score of 2 or higher);^{19,20} or (3) a score at or below 1.5 standard deviations from the mean in at least two cognitive domains based on test items that evaluate memory, orientation, and executive function. The NHATS dementia classification was previously validated against a consensus panel's research diagnosis of dementia for a sample of participants in the Health and Retirement Study's Aging, Demographics and Memory Study (ADAMS), which based its determination on a 3 to 4 hour structured in-home clinical assessment and medical records.²¹ Relative to ADAMS, the NHATS classification has 66% sensitivity and 87% specificity.²²

2.2 | Outcomes

We examined three sets of outcomes from the COVID-19 supplement: (1) self-reported infection with COVID-19 and measures to limit the spread; (2) social, behavioral, and emotional responses to the pandemic; and (3) changes in health-care use and communication with providers in response to the pandemic.

2.2.1 | Self-reported infection with COVID-19

Respondents were asked whether they ever had symptoms of COVID-19, had been told by a doctor they had COVID-19, or had tested

positive for COVID-19. We used responses to these items to create an indicator of any mention (symptoms, diagnosis, or positive test). Respondents were also asked if anyone they lived with had COVID-19 and, for those in residential care facilities, if staff or other residents had been infected.

2.2.2 | Measures to limit spread

Respondents were asked whether they had taken specific measures to limit the spread of COVID-19. We included six measures that apply across community and residential care settings: frequently wash or sanitize hands, avoid contact with co-resident people, avoid contact with non-resident people, maintain a distance of 6 feet, wear a face mask when going out, and avoid touching their face. In addition, those living in a facility were asked whether the facility: stopped or limited outside visitors, required residents to stay in rooms/units, required quarantine upon return to the facility, stopped meals in common areas, stopped group activities in common areas, stopped facility-provided transportation, required staff to wear masks, increased cleaning and disinfecting, and helped residents keep in touch online. We counted positive responses to these items to create an indicator of number of facility measures.

2.2.3 | Social, behavioral, and emotional responses

Respondents reported how often they had contact with non-resident family and friends before and during the pandemic. We examined frequency of contact by phone and for in-person visits, focused on changes from at least weekly to less-than-weekly contact. Respondents were also asked whether they spent more or less time in coping-related activities in a typical week during the pandemic. We focused on four coping activities that were relevant to both community and residential care settings: walking for exercise (less often), eating including snacking (more often), watching TV or online programs or movies (more often), and sleeping (more often). Respondents were also asked to report in a typical week how worried or anxious they felt about the pandemic and how sad or depressed they felt about the pandemic. We dichotomized responses into moderate or severe (some of the time on more than half the days, nearly every day, during the day and at night) versus mild (some days) or not at all.

2.2.4 | Health-care use and communication

Respondents were asked if during the pandemic there had ever been a time when they needed or planned to see a doctor or other health-care provider but put off getting care. Those who answered yes were asked to indicate the type of care they put off including seeing their usual doctor, seeing a specialist, a vision appointment, a hearing appointment, or a dentist or hygienist appointment. In addition, respondents were asked about the type of communication they had with their usual

health-care provider before and during the pandemic: phone calls, e-mails or texts or portal message, video calls (or telehealth), or in-person visits. We used this information to classify respondents who started phone, electronic, or video communication and who stopped in-person visits.

2.3 | Control variables

Control variables describing participants' demographic characteristics were drawn from the 2020 NHATS interview. Participant characteristics included age, sex, and race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic vs. Other groups); completed education (less than high school, high school degree or equivalent, more than high school); and for those in community settings, whether they lived alone or with others.

2.4 | Statistical analysis

We reported means and tested for differences in sample characteristics between those with and without dementia with *t* tests and X^2 tests (for continuous and categorical variables, respectively). We conducted these tests first across all settings combined and then separately for those living in community and residential care facilities. For dichotomous outcomes, we reported the percentage among those with and without dementia, *P*-values for X^2 tests, and adjusted odds ratios (AOR) and 95% confidence intervals (CIs) from logistic regression models controlling for age, sex, race/ethnicity, and education. For counts, we reported the mean number for those with and without dementia in each setting, *P*-values for *t* tests, and adjusted beta coefficients and 95% CI from ordinary least squares regression models. Analyses with Poisson regression models were explored and yielded nearly identical estimates. We also tested differences by setting (community vs. residential care) in the AOR for dementia by estimating models with an interaction between dementia and setting. All estimates used sample weights, taking into account differential probabilities of selection and response to NHATS and the COVID-19 supplement. Standard errors were adjusted to reflect the complex design of NHATS. Statistical analyses were performed using STATA v17.

3 | RESULTS

3.1 | Demographic characteristics by dementia and setting

Older adults with dementia were more likely than those without dementia to live in residential care settings (29.7% vs. 4.2%; $P < 0.001$) and were less likely to live alone in the community (17.1% vs. 27.1%; $P < 0.001$). Within residential care settings, those with dementia were more likely to be living in nursing home and assisted living settings ($P < 0.001$; Table 1). In both community and residential care set-

tings, those with dementia were on average older and more likely to have a proxy respond to the questionnaire than those without dementia ($P < 0.001$). In community settings, those with dementia also were more likely to report that their primary race/ethnicity was non-Hispanic Black or Hispanic ($P = 0.006$) and had fewer years of education ($P < 0.001$).

3.2 | COVID-19 infection and measures to limit spread

3.2.1 | Community settings

In community settings, there were no differences in adjusted models in reports of COVID-19 infection or in living with someone who had COVID-19 for those with and without dementia (Table 2). Yet, older adults with dementia were less likely than those without dementia to frequently wash or sanitize their hands (AOR = 0.27; 95% CI = 0.15–0.48), maintain a 6 foot distance (AOR = 0.48; 95% CI = 0.31–0.76), wear a mask (AOR = 0.31; 95% CI = 0.19–0.50), and avoid touching their face (AOR = 0.50; 95% CI = 0.34–0.75).

3.2.2 | Residential care settings

In residential care settings, those with dementia were more than five times as likely as those without dementia to have had symptoms of COVID-19 (AOR = 5.13; 95% CI = 1.07–24.64) and to report another resident or staff member had COVID-19 (AOR = 2.21; 95% CI = 1.18–4.14; Table 2). Those with dementia had a 12-fold higher risk than those without dementia of being diagnosed with COVID-19 (9.8% vs. 0.8%; $P < 0.001$). Measures taken to limit the spread of COVID-19 also varied by the presence of dementia in these settings. Those with dementia were more likely than others to have avoided contact with other residents (AOR = 4.77; 95% CI = 2.56–8.89) and non-residents (AOR = 3.39; 95% CI = 1.58–7.29); interaction tests suggested these AORs were larger in residential care than in community settings ($P < 0.05$). Older adults with dementia were also less likely to wear a face mask (AOR = 0.26; 95% CI = 0.11–0.62) or to avoid touching their face (AOR = 0.44; 95% CI = 0.25–0.81).

Older adults with dementia were more likely than those without dementia to live in facilities that undertook a greater number of measures to limit the spread of COVID-19 ($\beta = 1.69$, $P < 0.001$; Table 3). Nearly 95% of those with dementia lived in facilities that stopped or limited outside visitors (AOR = 7.53; 95% CI = 2.32–24.45) and three out of four required residents to stay in their unit or room (AOR = 4.26; 95% CI = 1.83–9.95) and to quarantine upon return to the facility (AOR = 3.60; 95% CI = 1.57–8.29). Older adults with dementia were also more likely than others to live in facilities that required staff to wear masks (AOR = 4.42; 95% CI = 1.41–13.82), increased cleaning and disinfecting (AOR = 7.41; 95% CI = 2.47–22.21), and increased help to residents to keep in touch with family and friends online (AOR = 3.87; 95% CI = 2.21–6.78).

TABLE 1 Characteristics of adults ages 70 and older in 2020 by residential setting

Characteristic (N)	All settings combined			Community settings			Residential care facilities		
	No dementia (2880)	Dementia (377)	P-value	No dementia (2735)	Dementia (272)	P-value	No dementia (145)	Dementia (105)	P-value
Age (years), M (SD)	77.7	84.7	<0.001	77.5	83.4	<0.001	84.1	87.9	0.001
Sex (%)			0.451			0.600			0.219
Male	44.4	41.5		44.8	47.3		35.5	27.7	
Female	55.6	58.6		55.2	52.7		64.5	72.4	
Race (%)			0.182			0.006			0.156
White, non-Hispanic	78.9	75.1		78.9	67.8		80.6	92.5	
Black, non-Hispanic	7.5	10.9		7.6	13.2		4.9	5.3	
Hispanic	9.2	9.4		7.2	13.3		7.3	-	
Other	6.3	4.7		6.3	5.7		7.2	2.2	
Education, (%)			<0.001			<0.001			0.930
Less than high school	12.5	26.3		12.5	31.4		13.7	14.2	
High school or equivalent	31.8	37.4		31.6	36.9		36.0	38.4	
More than high school	55.7	36.4		55.9	31.7		50.3	48.5	
Housing (%)			<0.001			0.304			-
Residential care	4.2	29.7		-	-		100.0	100.0	
Nursing home care	-	-		-	-		9.8	38.1	<0.001
Assisted living	-	-		-	-		15.5	50.2	
Independent living	-	-		-	-		74.8	11.7	
Community, alone	27.1	17.1		28.3	24.3				
Community, with others	68.7	53.2		71.7	75.7				
Proxy respondent (%)	7.5	71.4	<0.001	7.2	64.2	<0.001	13.6	88.5	<0.001

Abbreviation: SD, standard deviation.
 Bolded denotes statistical significant.

3.3 | Social, behavioral, and emotional responses

3.3.1 | Community settings

In community settings, changes in coping-related activities, but not in contact with non-resident family/friends or emotional responses, differed by the presence of dementia (Table 4). Older adults with dementia were less likely to report changes in walking for exercise (AOR = 0.64; 95% CI = 0.45–0.91); eating or snacking more often (AOR = 0.47; 95% CI = 0.27–0.85); or watching more television, movies, or online programs (AOR = 0.60; 95% CI = 0.42–0.86). However, older adults with dementia were twice as likely to report sleeping more often (AOR = 2.03; 95% CI = 1.36–3.04).

3.3.2 | Residential care settings

Unlike findings for community settings, in facilities frequency of contact with non-resident family or friends fell (from more than weekly

to less than weekly) more often for older adults with dementia (AOR = 6.30; 95% CI = 1.44–27.5 for phone and AOR = 3.64; 95% CI = 1.73–7.62 for in person). Changes in coping-related activities mirrored those in community settings: older adults with dementia were half as likely as those without dementia to increase time spent watching television, movies, or online programs (AOR: 0.47; 95% CI = 0.25–0.89) but more than three times as likely as those without dementia to sleep more (AOR = 3.39; 95% CI = 1.56–7.36). Older adults with dementia also were less likely to experience moderate or severe worry about COVID-19 (AOR = 0.37; 95% CI = 0.16–0.85).

3.4 | Changes in health care and health communications

3.4.1 | Community settings

In community settings, the percentage who put off seeking health care did not differ by dementia status, with one exception (Table 5): older

TABLE 2 Self-reported COVID-19 infection and measures to limit spread of COVID-19, by the presence of dementia among adults ages 70 and older

	Community settings				Residential care facilities					
	No dementia (N = 2735)	Dementia (N = 272)	P-value	AOR ^b	95% CI	No dementia (N = 145)	Dementia (N = 105)	P-value	AOR ^a	95% CI
Self-reported infection:										
Had symptoms of COVID-19	4.2	4.8	0.760	1.41	0.50, 4.03	2.5	10.1	0.023	5.13	1.07, 24.64
Diagnosed with COVID-19	1.6	1.2	0.662	0.92	0.28, 3.00	0.8	9.8	<0.001	19.82	2.52, 155.7
Tested positive for COVID-19	2.0	4.1	0.133	1.70	0.62, 4.64	4.3	12.2	0.057	3.43	0.96, 12.37
Any mention COVID-19 infection	5.1	7.7	0.267	1.58	0.66, 3.81	6.4	14.2	0.063	2.42	0.83, 7.07
Someone they lived with (or any resident or staff in the place they lived ^c) had COVID-19	1.7	2.0	0.743	1.57	0.53, 4.32	34.9	52.0	0.018	2.21	1.18, 4.14
Measures to limit spread:										
Frequently wash or sanitize hands	96.1	85.2	<0.001	0.27	0.15, 0.48	93.6	86.1	0.109	0.41	0.13, 1.31
Avoided contact with people live with	14.0	20.3	0.012	1.11	0.75, 1.65	19.7	57.9	<0.001	4.77 ^b	2.56, 8.89
Avoided contact with non-resident people	81.9	79.9	0.477	1.02	0.71, 1.48	71.1	89.0	0.002	3.39 ^b	1.58, 7.29
Distancing 6 feet	89.4	77.3	<0.001	0.48	0.31, 0.76	86.6	79.7	0.175	0.75	0.31, 1.79
Wore face mask	94.6	83.8	<0.001	0.31	0.19, 0.50	92.1	72.6	<0.001	0.26	0.11, 0.62
Avoided touching face	85.5	71.4	<0.001	0.50	0.34, 0.75	77.2	58.0	0.005	0.44	0.25, 0.81

^a Adjusted for age, sex, race/ethnicity, education.

^b Significantly different from AOR for dementia for those living in community settings.

^c Asked only of those living in residential care facilities.

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval.

Bolded denotes statistical significant.

TABLE 3 Facility measures to limit spread of COVID-19, by the presence of dementia among adults ages 70 and older living in residential care facilities

	No dementia (N = 2735)	Dementia (N = 272)	P-value	AOR ^b	95% CI
Number of measures ^a	5.1	7.3	<0.001	1.69	0.76, 2.62
Stopped or limited outside visitors	70.0	94.9	0.002	7.53	2.32, 24.45
Required residents to stay in rooms/units	39.6	76.4	<0.001	4.26	1.83, 9.95
Required quarantine upon return	44.0	73.9	<0.001	3.60	1.57, 8.29
Stopped meals in common areas	57.7	71.8	0.126	1.39	0.57, 3.39
Stopped group activities in common areas	63.5	77.1	0.129	1.40	0.58, 3.40
Stopped facility-provided transportation	59.4	74.2	0.060	1.59	0.78, 3.26
Required staff to wear masks	73.3	93.5	0.003	4.42	1.41, 13.82
Increased cleaning and disinfecting	65.8	94.0	<0.001	7.41	2.47, 22.21
Helped residents keep in touch online	40.2	75.5	<0.001	3.87	2.21, 6.78

^aAdjusted beta coefficient from ordinary least squares regression models are presented in AOR column.

^bAdjusted for age, sex, race/ethnicity, education.

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval.

Bolded denotes statistical significant.

adults with dementia were less likely than those without dementia to put off seeking dental care (AOR = 0.51; 95% CI = 0.32–0.81).

3.4.2 | Residential care settings

In facilities, older adults with dementia were less likely than those without dementia to put off seeking health care overall (AOR = 0.35; 95% CI = 0.18–0.70) and specifically vision (AOR = 0.23; 95% CI = 0.10–0.52) and dental (AOR = 0.25; 95% CI = 0.10–0.62) care. Older adults with dementia were also more likely to start electronic communication (e-mails/texts/portal messaging; $P = 0.019$), although rates were low (6.7%). Among those with dementia, 28% started telehealth visits (AOR = 3.29; 95% CI = 1.38–7.84) and 42% stopped in-person health-care visits (AOR = 2.12; 95% CI = 1.07–4.19). The AOR for dementia for stopping in-person health-care visits was significantly different between residential care (2.12) and community settings (0.81; $P < 0.05$ for difference).

4 | DISCUSSION

Using nationally representative data for the United States, we documented several key differences among older adults' experiences in the first wave of the COVID-19 pandemic by residential setting and by the presence of dementia. First, consistent with prior studies,⁴ symptoms and diagnosis of COVID-19 were substantially higher for those living with dementia; however, this result held only in residential care settings. This finding is likely attributable to those with dementia being less able to undertake measures to limit the spread and living in types of residential care (e.g., nursing homes) where caseloads were particularly high during the first half of 2020.²³

Second, unlike older adults without dementia and those with dementia living in the community, nearly all (95%) of older adults with dementia in residential care settings lived in places that stopped or limited outside visitors and three fourths were required to stay in their rooms. This finding may be linked to the fact that older adults with dementia in residential care settings were more likely to live in nursing home and assisted living facilities, where quarantines were more likely to be imposed, whereas those without dementia were more likely to live in independent living facilities.¹³ Irrespective of the reason, nearly half of older adults with dementia in residential care changed to less than weekly contact with non-resident family or friends; in contrast, only ≈20% of those without dementia in residential care and those with and without dementia in community settings changed to less than weekly contact.

Third, patterns of coping behaviors differed for older adults with and without dementia, with fewer differences by setting. In both community and residential care settings, those with dementia had 2 to 3 times the odds of those without dementia of sleeping more often. Prior studies have linked excessive daytime sleep to poor health outcomes,²⁴ a particular concern in residential care settings, where more than 4 out of 10 with dementia were reported to be sleeping more often during the first wave of the pandemic. In both settings those with dementia were also far less likely than those without dementia to increase sedentary and passive behaviors such as watching television, movies, or online programs; however, we could not determine whether this pattern was attributable to less frequent participation in these behaviors before the pandemic by those living with dementia. A growing literature has documented neuropsychiatric symptoms of apathy and anxiety among those living with dementia during the COVID-19 pandemic linked to long bouts of isolation.^{25,26} Our findings that 17% to 25% of those with dementia reported moderate or severe worry/sadness about the pandemic are consistent with this literature;

TABLE 4 Social, behavioral, and emotional responses to the COVID-19 pandemic, by the presence of dementia, adults ages 70 and older

	Community settings				Residential care facilities			
	No dementia (N = 2735)	Dementia (N = 272)	P-value	AOR ^b 95%CI	No dementia (N = 145)	Dementia (N = 105)	P-value	AOR ^b 95% CI
Change to less than weekly contact with non-resident family/friends by:								
Phone	5.0	7.4	0.131	1.77 0.93, 3.37	3.2	15.9	0.029	6.30 1.44, 27.5
In-person visits	22.9	20.9	0.712	1.20 0.62, 2.31	18.6	48.1	<0.001	3.64^c 1.73, 7.62
Changes in coping-related activities:								
Walking for exercise less often	13.3	4.0	<0.001	0.64 0.45, 0.91	39.9	33.5	0.414	0.75 0.38, 1.44
Eating/snacking more often	19.0	7.0	<0.001	0.47 0.27, 0.85	14.5	4.5	0.051	0.32 0.08, 1.31
TV/movies/online programs more often	42.4	23.4	<0.001	0.60 0.42, 0.86	40.3	22.4	0.013	0.47 0.25, 0.89
Sleep more	15.7	25.0	0.004	2.03 1.36, 3.04	15.7	40.8	<0.001	3.39 1.56, 7.36
Emotional responses:								
Moderate/severe worry about COVID-19	29.0	23.2	0.178	0.88 0.54, 1.42	29.6	17.3	0.061	0.37 0.16, 0.85
Moderate/severe sadness about COVID-19	22.6	19.1	0.320	0.89 0.55, 1.44	24.9	24.7	0.980	0.75 0.36, 1.54

^a Adjusted beta coefficient from ordinary least squares regression models are presented in AOR column.

^b Adjusted for age, sex, race/ethnicity, and education.

^c Significantly different from AOR for dementia for those living in community settings.

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval.

Bolded denotes statistical significant.

TABLE 5 Changes in healthcare and communication with providers in response to the COVID-19 pandemic, by the presence of dementia

	Community settings				Residential care facilities					
	No dementia (N = 2735)	Dementia (N = 272)	P-value	AOR ^a	95% CI	No dementia (N = 145)	Dementia (N = 105)	P-value	AOR ^a	95% CI
Put off seeking health care	38.3	32.7	0.174	1.01	0.66, 1.52	49.8	26.3	0.005	0.35^b	0.18, 0.70
Seeing usual doctor	18.6	19.9	0.763	1.20	0.65, 2.18	21.1	10.9	0.095	0.48	0.19, 1.21
Seeing a specialist	15.1	15.7	0.842	1.34	0.83, 2.17	25.6	15.8	0.174	0.63	0.27, 1.48
Vision appointment	13.7	10.0	0.239	0.78	0.43, 1.42	29.3	9.2	<0.001	0.23^b	0.10, 0.52
Hearing appointment	2.9	2.2	0.522	0.58	0.24, 1.44	12.0	6.4	0.208	0.40	0.12, 1.26
Dentist or hygienist appointment	21.0	7.9	<0.001	0.51	0.32, 0.81	28.5	10.1	0.006	0.25	0.10, 0.62
Changed communication mode with health-care providers										
Started phone call communication	18.1	14.9	0.240	0.74	0.51, 1.13	16.6	13.4	0.553	0.80	0.36, 1.78
Started e-mails/texts/portal message communication	5.8	5.5	0.886	1.40	0.68, 2.86	1.1	6.7	0.019	-	-
Started video calls (telehealth) communication	16.9	16.1	0.768	1.45	0.92, 2.28	13.1	28.4	0.026	3.29	1.38, 7.84
Stopped in-person visits	32.1	23.9	0.022	0.81	0.56, 1.18	26.9	42.6	0.043	2.12^b	1.07, 4.19

^a Adjusted for age, sex, race/ethnicity, education.

^b Significantly different from AOR for dementia for those living in community settings ($P < 0.05$).

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval.

Bolded denotes statistical significant.

however, we found similar levels across settings and by the presence of dementia.

Finally, consistent with prior studies, we found that in both community and residential care settings, older adults delayed health-care visits in substantial numbers; however, those with dementia were less likely to delay care if they lived in residential care settings.¹⁰ How to interpret this finding is unclear. It may be that older adults with dementia in residential care settings have more consistent access to health care; alternatively, they may be less likely to have regular care and therefore less likely to delay care. Like prior studies,⁹ we observed uptake of telehealth visits, but we documented that the percentage starting telehealth (28%) and stopping in-person visits (42%) was greatest for those with dementia in residential care settings, suggesting an important role for long-term care staff in keeping residents connected to health-care providers.

This study has several limitations worth noting. Given the retrospective design of the study, we cannot rule out the possibility of recall bias, although the time frame of interest was relatively short (for most 5–6 months). Proxy response rates were higher for those living with dementia (71% vs. 8%) and it could be that proxy respondents may recall experiences of participants differently than older adults who respond for themselves. Further, perceptions of hand washing and other precautionary measures to limit the spread of COVID-19 may differ by dementia or proxy status. We also did not attempt to classify respondents by stage of dementia; identifying the experiences for those with mild cognitive impairment should be explored. Sample size limitations resulted in substantial differences in group sizes and precluded further stratification of residential care settings for those with and without dementia. Finally, the results presented cover a description of the first wave of the pandemic during 2020 prior to widespread vaccination efforts; more recent experiences are not represented and we do not attempt to ascribe causality. Future studies linking differences in COVID-19 precautionary measures to objective health outcomes, such as Medicare claims, is warranted.

Findings add to our understanding of the disproportionate impact of the COVID-19 pandemic on the care needs and well-being of older adults living with dementia, particularly in residential care settings. Previous studies have underscored excess mortality among those with dementia, particularly in residential care settings.²⁷ Our findings extend this literature by highlighting that those with dementia in residential care settings were much more likely to be diagnosed with COVID-19 or to have had symptoms of COVID-19 than those without dementia in these settings. We also found that in both community and residential care settings, a substantial share of older adults with dementia coped with the onset of the pandemic by sleeping more. Further, older adults living in residential care settings were subjected to widespread restrictions on visitors and contact with other residents,^{28,29} which our findings suggest resulted in nearly half of those with dementia receiving less than weekly in-person visits. Others have called attention to the need to bolster infection prevention in residential care settings—for instance, by distancing during group activities and implementing masking requirements.³⁰ Taken together with our findings, alternative strategies that stop short

of avoiding contact altogether are needed for those living with dementia, as such actions may help attenuate the disproportionate social and behavioral consequences for those living with dementia in these settings.

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CONFLICTS OF INTEREST

The authors have no conflicts to report. [Author disclosures](#) are available in the supporting information.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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