

**BRIEF REPORT**

# Care disruptions among the homebound during the COVID-19 pandemic: an analysis of the role of dementia

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**Funding information**

National Institute on Aging, Grant/Award Numbers: K23AG066930, R01AG060967

**Abstract**

**Introduction:** Seriously ill people with dementia living at home may be particularly vulnerable to disruptions in their care during times of crisis. The study sought to describe care experiences of those receiving home-based primary care in New York City during the COVID-19 pandemic and compare the experiences of people with and without dementia.

**Methods:** We conducted a retrospective review of all electronic medical record notes between March 1, 2020 and December 30, 2020 among a sample of home-based primary care recipients ( $n = 228$ ), including all deaths that occurred in the spring of 2020. Drawing from administrative records and using an abstraction tool that included both structured (e.g., documented COVID-19 exposure) and unstructured (e.g., text passage describing caregiver burden) data, we identified salient COVID-19 related care experiences and identified and categorized major disruptions in care.

**Results:** Both people with and without dementia experienced significant disruptions of paid caregiving, family caregiving, and home-based services during the COVID-19 pandemic. While the paid caregivers of people with dementia reported more burden to the home-based primary care team as compared to people without dementia, we found little evidence of differences in quantity or type of COVID-19 related disruptions relative to dementia status.

**Discussion:** While those with dementia have distinct care needs, our findings emphasize the way that dementia may be one piece of a larger clinical picture of serious illness. In order to support all patients with high care needs in crisis, we need to understand the interdependence of clinical care, long-term care, and family caregiving support for older adults and view dementia within the larger context of serious illness and care need.

**KEYWORDS**

caregiving, COVID-19, dementia, home-based primary care, homebound

## INTRODUCTION

As a growing population of older adults ages in place, home-based medical care has emerged as a successful approach to support individuals with the most complex medical and social needs.<sup>1-3</sup> While individuals with a wide range of clinical conditions receive and may benefit from home-based medical care, evidence suggests that this model is particularly important for people with dementia, many of whom who may have difficulty accessing traditional office-based care.<sup>4-6</sup> Currently over 60% of homebound fee-for-service Medicare beneficiaries who receive home-based medical care have a diagnosis of dementia.<sup>7</sup>

The COVID-19 pandemic has accelerated shifts in the locus of long-term care from institutions to communities and deepened interest in models that deliver medical care at home.<sup>8,9</sup> Yet research about COVID care experiences to date has primarily focused on care in hospitals, nursing homes, and other institutional settings.<sup>10-12</sup> The available literature has revealed challenges unique to delivering care in the home setting in times of crisis, including challenges coordinating among networks of care providers and implementing telehealth.<sup>9,13-15</sup> Because of their cognitive impairment and disproportionate reliance on caregivers, people with dementia may be especially impacted by disruptions in home-based care and require additional support.<sup>16</sup>

We conducted a retrospective medical record review of individuals receiving home-based primary care in New York City during the COVID-19 pandemic in order to (1) understand care experiences during this crisis and (2) compare care experiences among patients with and without dementia. We hypothesized that those with dementia would experience more documented care disruptions (e.g., caregiving changes, missed or altered services) as compared to those without dementia.

## METHODS

### Study design and setting

We performed a retrospective review of electronic patients records between March 1, 2020 and December 30, 2020 for a sample of individuals receiving care from the Mount Sinai Visiting Doctors Program (MSVD), an academic home-based primary care program located in Manhattan whose interdisciplinary team cares for over 1200 patients annually.<sup>17</sup>

### Sample

We identified all MSVD patients active as of March 1, 2020 ( $n = 1223$ ). First, in order to capture the sickest

### Key points

- While COVID-19 profoundly disrupted the care of medically complex and functionally impaired homebound people, we found little evidence of differences in quantity or type of COVID-19 related experiences relative to dementia status.
- These findings suggest that for those with significant medical and functional care needs living in the community, dementia may be only one aspect of complex serious illness.

### Why does this paper matter?

Dementia diagnoses should be viewed within the larger context of serious illness and care need in order to ensure that all those with high care needs living in the community receive needed supports in a crisis.

patients who were most likely to experience care disruptions due to COVID-19 we identified all patients who died between March 1, 2020 and June 30, 2020 ( $n = 112$ ). This period coincided with the initial COVID-19 case surge in New York City.<sup>15</sup> Second, in order to also include patients who received routine care during the pandemic we then took a random sample of approximately 10% of all individuals who survived the first wave of the pandemic in New York City ( $n = 116$ ). This resulted in a final sample of 228 patients whose medical records were then reviewed between March 1, 2020 and either time of death or December 30, 2020.

### Data collection

#### Sample characteristics

Data on patient sociodemographic characteristics (i.e., age, gender, race/ethnicity, marital status, receipt of Medicaid) and clinical characteristics (i.e., chronic conditions as determined by the Elixhauser score, length of enrollment in MSVD) were obtained from an administrative database. Dependency in activities of daily living (i.e., ambulation, feeding, dressing, grooming, bathing, toileting, incontinence), dependency in instrumental activities of daily living (i.e., telephone use, shopping, food preparation, housekeeping, hours repairs, laundry,

transportation, taking medications, financial management) and care context (i.e., lives alone, has any paid care, lives in government-subsidized housing, lives in congregate housing) were obtained by manual record review. Dementia diagnosis was determined by a dementia-related diagnosis in the electronic medical record (e.g., Alzheimer's Disease, vascular dementia) and confirmed via manual record review.

## COVID-19 experiences

Information about COVID-19 related care experiences was obtained by analyzing medical record notes collected through an abstraction tool, which was developed by the project team in REDCap based on literature review, clinical expertise, and independent review of four patient records. The tool captured structured data about COVID-19 experiences (i.e., COVID-19 exposure, death due to confirmed/presumed COVID-19, hospice enrollment, and documented conversations about delaying or avoiding hospitalization due to COVID-19), as well as unstructured clinical notes within three a priori categories of COVID-related care disruptions (i.e., paid caregiving disruptions, family caregiving disruptions, and home-based service disruptions). Paid caregiving disruptions were defined as those related to home health aides or other home care workers. Family caregiving disruptions were defined as those related to spouses, children, friends, or other unpaid caregivers. Home-based service disruptions considered nursing, hospice, and other home-based services. The research team reviewed and refined these categories iteratively throughout the analytic process, recoding records as necessary.

Author PK abstracted all electronic patient record data. A random sample of 10% of cases was reviewed for accuracy by a second researcher EX; disagreements were few and were resolved through discussion until reaching consensus. When clinical questions were flagged by either PK or EX (e.g., COVID-19 as cause of death), MSVD clinicians MZ and JR provided additional record review.

## Analysis

Data about COVID experiences were analyzed using two complementary approaches. First, structured data about COVID-19 experiences (e.g., COVID-19 exposure) among people with and without dementia were compared using chi square and t-tests. Second, unstructured text was analyzed using the Framework Method of qualitative data analysis, which involves first summarizing passages of

text and then arranging them in a chart to facilitate comparing and contrasting data between subgroups.<sup>18</sup> Blinded to patient dementia status, two researchers (JR and PK) reviewed all passages of text and created succinct data summaries of each care disruptions for each patient. Within each a priori category of COVID-related care disruption, sub-categories were created in order to further organize the data. "Paid caregiving disruption" was divided into increased paid caregiver burden, change in care schedule, and administrative delays; "family caregiving disruption" was divided into increased family caregiver burden, decreased in-person involvement; and "home-based service disruptions" was divided into home-based clinical care disruption and medical equipment disruption. Data summaries were placed in a chart, which was then separated into people with and without dementia. The full research team then reviewed and discussed the charts of summarized data to determine differences between the two groups.

The project was approved by the Icahn School of Medicine at Mount Sinai's Institutional Review Board.

## RESULTS

### Sample characteristics

Of the 228 patients, nearly 60% ( $n = 135$ ) had dementia. As compared to people without dementia, people with dementia were older (mean age 89.6 vs. 78.4,  $p < 0.001$ ) and more likely to be female (80.0% vs. 63.4%,  $p = 0.01$ ). They were also more likely to receive support from a paid caregiver (88.2% vs. 73.1%,  $p = 0.003$ ), more likely to be dependent in all activities of daily living (43.0% vs. 21.5%,  $p = 0.001$ ), and less likely to live alone (43.0% vs. 55.9%,  $p = 0.05$ ). Finally, those with dementia were more likely to have died during the study period (66.7% vs. 45.2%,  $p = 0.001$ ) as compared to those without dementia (Table 1).

### COVID-19 experiences

There were few substantive differences between the COVID-19 care experiences of those with and without dementia (Figure 1). People with and without dementia experienced similar proportions of documented COVID exposures (17.8% vs. 21.5%,  $p = 0.48$ ), deaths due to COVID-19 (15.6% vs. 16.1%,  $p = 0.91$ ), hospice enrollments (20.7% vs. 16.1%,  $p = 0.38$ ), and conversations about delaying or avoiding hospitalization due to concerns about COVID-19 (20.0% vs. 21.5%,  $p = 0.78$ ).

A wide range of disruptions in paid caregiving, family caregiving, and home-based services were documented:

TABLE 1 Characteristics of the sample by dementia status

	Total sample (n = 228)	People with dementia (n = 135)	People without dementia (n = 93)	p-value
<b>Patient characteristics</b>				
Age, mean (SD)	85.1 (13.0)	89.6 (7.9)	78.5 (15.8)	<0.001
Female, %	73.3	80.0	63.4	0.01
Race/ethnicity				0.26
Black, %	10.1	7.41	14.0	
Latino/a, %	23.3	26.7	18.3	
White, %	47.8	47.4	48.4	
Other, %	8.9	19.4	19.4	
Medicaid, %	46.1	44.4	48.4	0.56
Married, %	18.9	23.0	12.90	0.06
<b>Clinical and Functional Characteristics</b>				
Elixhauser score, mean (SD)	4.07 (2.42)	3.89 (2.42)	4.32 (2.41)	0.18
Dependent in all ADLS <sup>a</sup> , %	34.2	43.0	21.5	0.001
Dependent in all IADLS <sup>b</sup> , %	15.8	17.0	14.0	0.53
Months enrolled in MVSD, mean (SD)	1551.7 (975.6)	1475.2 (970.5)	1604.4 (979.3)	0.33
Died during the study period, %	59.2	66.7	45.2	0.001
<b>Care context</b>				
Lives alone, %	48.3	43.0	55.9	0.05
Has any paid care <sup>c</sup> , %	82.0	88.2	73.1	0.01
Lives in government-subsidized housing, %	14.9	17.8	10.8	0.14
Lives in congregate housing, %	8.3	4.4	14.0	0.01

<sup>a</sup>ADL = activities of daily living (i.e., ambulation, feeding, dressing, grooming, bathing, toileting, incontinence).

<sup>b</sup>IADL = instrumental activities of daily living (i.e., telephone use, shopping, food preparation, housekeeping, hours repairs, laundry, transportation, taking medications, financial management).

<sup>c</sup>Paid care = long-term care from home health aides or other home care workers.

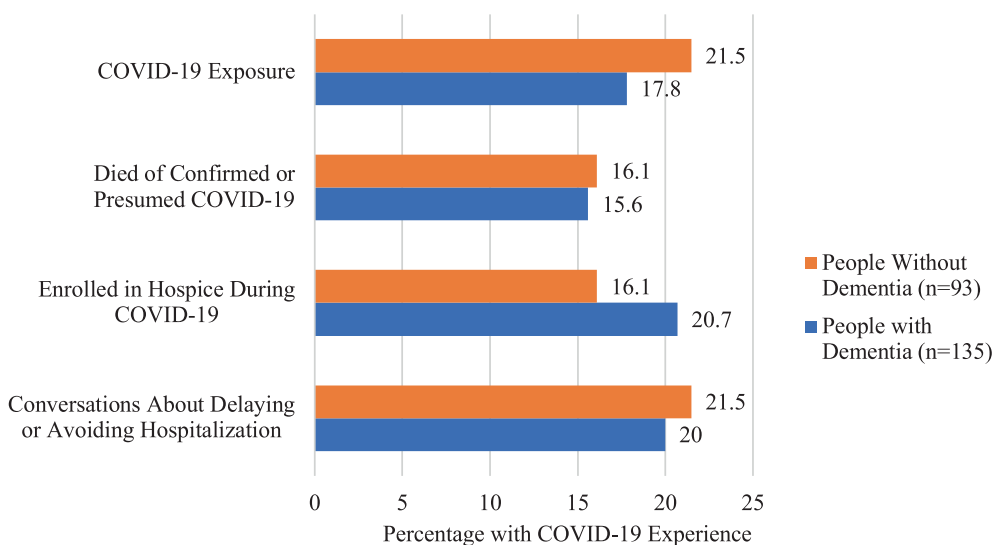


FIGURE 1 Title: comparisons of COVID-19 experiences between those with and without dementia

of all patient records reviewed, 26.3% had a documented disruption related to paid caregiving, 46.7% had a documented disruption related to family caregiving, and

44.2% had a documented disruption in a home-based service. Table 2 provides examples of COVID-19 related care disruptions related to each subcategory and presents

TABLE 2 Comparison of COVID-related care disruptions between people with and without dementia

Disruptions	Example	Role of dementia
Paid caregiving disruptions		
Increased paid caregiver burden	“Aide sees small amount of blood on the floor...while on the phone with me and becomes...more upset. She says she cannot care for patient in the home this way.” (Patient 43, no dementia, primary physician)	Paid caregivers of those with dementia experienced more emotional burden than those without dementia, especially when asked to take on additional care tasks.
Change in care schedule	“The [aides] tested positive for COVID 19...all the [home care] services have been canceled. Until patient gets tested, [her daughters] are taking care of patient.” (Patient 44, no dementia, registered nurse)	Schedule changes were common for both people with and without dementia, particularly when paid caregivers were exposed to or tested positive for COVID-19.
Administrative delays	“Daughter...says hospice was supposed to send someone 2 hours daily but this has not happened.... Given COVID, people are not available, agencies not adding hours, etc.” (Patient 80, dementia, covering physician)	Delays in home assessments and challenges staffing cases were common for both people with and without dementia.
Family caregiving disruption		
Increased burden	“Aide has COVID-19...His in-laws who live with them are sick...His kids and wife are not coming to the back of the house...He is going to have to take care of his mother himself.” (Patient 101, no dementia, primary physician)	Family caregivers of both people with and without dementia experienced high levels of burden as systems of support (e.g., paid caregivers, clinical home visits) were upended due to COVID-19.
Decreased in-person involvement	“[Daughter] prefers patient to be managed at home due to fear of COVID pandemic, she has not visited patient for 10 weeks for this reason.” (Patient 103, dementia, nurse practitioner)	Family caregivers of both people with and without dementia managed care from afar as even local caregivers kept physical distance to reduce COVID-19 exposure.
Home-based service disruptions		
Home-based clinical care disruptions	“Left great toe and left calf are unstageable. She would like a verbal order from [physician] to decrease wound visits... They have minimal staff due to COVID.” (Patient 28, dementia, registered nurse)	Both people with and without dementia experienced care disruptions due to staffing and personal protective equipment shortages disrupted care from certified home health agencies, hospices, and other providers.
Medical equipment disruptions	“Granddaughter called asking for an urgent oxygen tank...Will not be able to get oxygen into the home in a timely fashion due to issues with the supply chain.” (Patient 222, no dementia, covering physician note)	Both people with and without dementia experienced delays in equipment delivery and repair.

summative comparisons of the experiences of people with and without dementia. The only meaningful difference in care disruptions between people with and without dementia that was documented in the medical record was that paid caregivers of patients with dementia experienced more documented emotional challenges related to providing home care during COVID-19.

## DISCUSSION

While COVID-19 profoundly disrupted the care of medically complex and functionally impaired homebound people, we found little evidence of differences in quantity

or type of COVID-19 related experiences relative to dementia status. These findings provide important insights into how regardless of specific diagnoses, those with high care needs living in the community require targeted support in a crisis.

Both people with and without dementia faced a wide range of care disruptions during the COVID-19 pandemic, which highlights their high degree of dependence on paid caregivers, family caregivers, and home-based services. Long-term services and supports (e.g., paid caregiving, home-delivered meals) in the home in particular may be vulnerable in times of crisis such as the COVID-19 pandemic.<sup>19,20</sup> Such services are funded by a patchwork of payers; Medicaid is the primary government



payer of long-term care, but coverage varies significantly state by state and patients and families frequently pay privately for additional care to supplement the large amounts of care that families provide themselves.<sup>21–23</sup> The COVID-19 pandemic has underscored how this direct care is necessary to support other care in the home and community and has brought attention to the need to further support both family and paid caregivers.<sup>24,25</sup>

The care disruptions experienced by people with and without dementia were severe and debilitating, but not dissimilar; even family caregiver disruptions were similar between the two groups. These findings suggest that while focus on the special care needs of the dementia population is important and appropriate relative to types of care needs (e.g., management of behavioral symptoms), classifying patients into two distinct buckets (with dementia, without dementia) may obscure the overlapping conditions and shared experiences faced by patients living with an array of serious illnesses and comorbid conditions. As a result, it is important to conceptualize serious illness in a way that acknowledges that dementia is one subgroup that may overlap with other serious illness manifestations.<sup>26</sup> This enables consideration of the ways that dementia is unique while at the same time acknowledging that dementia may at times be just one piece of a larger clinical picture.

One notable exception in which COVID-19 care experiences varied by dementia status was relative to the experience of paid caregivers: more paid caregiver burden was reported among people with dementia. This may be in part due to the unique challenges paid caregivers face when caring for those with dementia.<sup>27</sup> While those who self-direct care can problem solve on their own, additional responsibility likely falls to paid caregivers of those with dementia when care deviates from the established care plan. Given the challenges the larger home care system faced during the COVID-19 pandemic, these findings are not unexpected but emphasize the need for paid caregiver training and support specific to the care needs of people with dementia.<sup>28–30</sup>

A key limitation of our study is that we are only able to capture the elements of the COVID-19 experience that were reported to and documented by the home-based medical care team; while documented care disruptions existed for nearly 60% of records reviewed, this likely represents a vast underestimate of the actual disruptions experienced by patients and their families. However, these were events that were the most clinically significant and may be particularly meaningful considerations for medical providers caring for older adults. Our findings may not be generalizable beyond an urban population in NYC where our sample was drawn; while family

caregiving is ubiquitous, our findings may be less relevant for those in other environments who do not have access to similarly high levels of paid care and home-based services. However, our diverse sample provides important insight into care disruptions across the socioeconomic spectrum. Finally, while we compared people with and without dementia our sample size limited our ability to assess characteristics of those with dementia (e.g., dementia severity, behavioral disruptions) that may have also impacted care disruptions.

Homebound people both with and without dementia relied on paid caregivers, family caregivers, and home-based services during the COVID-19 pandemic; the disruptions of these supports created clinically significant care challenges regardless of dementia status. In order to better support homebound patients in a crisis, we need to view dementia within the larger context of serious illness and care needs and acknowledge the interdependence of clinical care, long-term care, and family caregiving support for all those with high care needs.

#### **AUTHOR CONTRIBUTIONS**

Authors Jennifer M. Reckrey, Emily Franzosa, and Katherine A. Ornstein were involved in the study concept and design, authors Jennifer M. Reckrey, Patricia S. Kim, Emily Xu, Meng Zhang, and Emily Franzosa were involved in acquisition of data, authors Jennifer M. Reckrey, Patricia S. Kim, Duzhi Zhao, Emily Franzosa, and Katherine A. Ornstein were involved in the analysis and interpretation of data, and all authors were involved in the preparation of the manuscript.

#### **CONFLICT OF INTEREST**

The authors have no conflicts.

#### **SPONSOR'S ROLE**

The study sponsors had no role in the design, methods, data collection, analysis, and preparation of the paper.

#### **FINANCIAL DISCLOSURES**

This work was funded by the National Institute on Aging (R01AG060967 and K23AG066930).

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**How to cite this article:** Reckrey JM, Kim PS, Zhao D, et al. Care disruptions among the homebound during the COVID-19 pandemic: an analysis of the role of dementia. *J Am Geriatr Soc*. 2022;1-8. doi:[10.1111/jgs.18008](https://doi.org/10.1111/jgs.18008)