

Short Communication

Living with Dementia During the COVID-19 Pandemic: A Nationwide Survey Informing the American Experience

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Abstract. Persons living with dementia and their caregivers are among society's most vulnerable, a condition exacerbated by the COVID-19 pandemic. This national survey was conducted with dementia caregivers in the US. Primary outcomes targeted pandemic-related changes in cognitive, behavioral, and motor systems. 113 dementia caregivers from 30 US states completed the survey. The impact of the COVID-19 pandemic on persons living with dementia and their caregivers is substantial in comparison to society at large. A marked public health and preventative role signals opportunity for practitioners to fill the void and prepare for future public health emergencies.

Keywords: Alzheimer's disease, behaviors, caregiving, COVID-19, dementia, neuropsychiatric symptoms, pandemic, public health emergency

INTRODUCTION

More than 6 million Americans have Alzheimer's disease or related dementias (ADRD) and approximately 85% live in the community [1, 2]. With prevalence in the United States (US) expected to near 14 million by 2050, ADRD has been identified as a rising epidemic with urgent need for intervention [1, 3]. Alzheimer's disease is characterized as a progressive and irreversible deterioration in cognitive ability negatively impacting one's ability to live and function independently [4]. Decreased cognition paired with neuropsychiatric symptoms and

physical dependence often leads to challenging situations for caregivers who are experiencing concurring lifestyle/role changes of their own.

Persons living with dementia (PLWD) regularly rely on informal/unpaid caregivers for daily support and safety and such support comes at an extraordinary cost to the caregiver. In the US, there are approximately 15.7 million informal or family caregivers of PLWD that forgo their lives to provide such support [5]. Reports suggest that as many as 80% of caregivers of PLWD experience high levels of stress [6] and nearly 40% experience significant depressive episodes [7]. Female caregivers, those going through multiple life events/changes, and caregivers lacking significant social networks have the highest risk for CG-related distress [8] which is often described as the result of a mix of circumstances, experiences, responses, and resources [9].

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On January 20, 2020, the Centers for Disease Control and Prevention (CDC) reported the first laboratory-confirmed COVID-19 in the US; by March 11th the World Health Organization declared a global pandemic and US states began to shut down to prevent spread [10]. As of November 2022, COVID variants remain within the US and aging/vulnerable adults are encouraged to continue preventative measures to protect themselves [11].

People with dementia and their caregivers have historically been among society's most vulnerable. Rodeheaver & Datan [12] surmised "As probably one of the most excluded groups in society, people with dementia experience the double jeopardy of being (aging) people with a cognitive impairment" (p.1). COVID-related restrictions to manage the pandemic in the US have amplified this inequity. For more than 2 years, PLWD and their caregivers have been asked to isolate from support systems, change routines, and decrease service use [13, 14]. Prolonged isolation can further feelings of loneliness, behavioral disruptions, and acute events, all while medical care is less accessible [14]. PLWD are less likely to adhere to precautions and have a markedly greater risk of experiencing a COVID infection than peers [15]. Mortality in infection is 40% higher than in peers as well, with 20% of PLWD with COVID living less than 6 months [16].

Despite the many negative outcomes associated with the COVID-19 pandemic, some have reported positive aspects from the caregiving experience in this time. As reported by Tulloch, McCaul, & Scott [17], mandated isolation allowed for a strengthened connection for the person living with dementia and their caregiver and a renewed/greater sense of meaning in the caring experience. Though present research suggests more obstacles than opportunities remain.

METHODS

Sample and settings

This study was approved by the Institutional Review Board (IRB # 1901305-1). The cross-sectional national survey was released in the Spring of 2022 and utilized a paid social media clickable advertising algorithm targeting individuals who identified with the dementia caregiving community. A total of \$500 (USD) was budgeted and spent for recruitment. Inclusion criteria were persons living within the US, 18 years or older, and that cared for

someone living with dementia during the COVID-19 pandemic.

Measures

Dementia stage was assessed with the Clinical Dementia Rating [18] and the primary and secondary outcomes from a semi-structured questionnaire created by Rainero et al. [19]. The primary outcomes were to identify changes in cognitive, behavioral, and motor symptoms in PLWD. Secondary outcomes were to identify effects on caregivers' well-being.

Statistical analysis

We completed statistical analysis using SAS software, version 9.4M7. We completed descriptive analysis of demographic and clinical baseline data. We then completed univariable and multivariable logistic regression of the dependent variables on the collected independent variables using mixed effects logistic regression. Regressors with significant p values in univariable logistic regression were included in multivariable regression. Bonferroni correction was applied to all the p -values of multivariable analysis, considering all outcomes together. Statistical significance was set at $p < 0.05$.

RESULTS

Demographics

Demographics are detailed in Table 1. The mean age of persons living with dementia was 80 years ($SD=9.4$), the majority were female (51%) with a disease duration of nearly 6 years ($SD=4.4$) at the time of data collection. The mean age of caregivers was nearly 64 ($SD=9.9$), predominantly female (95%), and were primarily "spouses".

Clinical information

Clinical information is detailed in Table 2. Perceived cognitive changes during the pandemic were reported in 80% of the PLWD. Perceived changes in behavioral symptoms were reported in 78% of the sample, with an average of 2.04 new symptoms appearing during the public health emergency. Perceived motor symptom changes were apparent in 81% of the sample. Healthcare service availability is reported in Table 3, where dementia services were reportedly reduced in more than 70% of cases, hos-

Table 1
Demographic information

	Total (n = 113)
Persons living with dementia	
Age (y, mean, SD)	80.27 (9.36)
Gender (female, %)	51.3
Regional distribution	
West (%)	23
Midwest (%)	14
North-East (%)	42
South (%)	24
Caregivers	
Age (y, mean, SD)	63.7 (9.96)
Sex (female, %)	107 (94.7)
Living together (yes, %)	72 (64.3)
Relationship Type	
Spouse (%)	42.5
Child (%)	33.6
Friend (%)	0.9
Sibling (%)	2.7
Other (%)	20.4

pitalization unavailable in nearly 30%, and a lack of urgent service availability for dementia-specific needs including cognition and behavioral symp-

toms, as well as significantly reduced availability of semi-residential/residential services (e.g., adult day programs).

Caregivers reported significant life disruption with the onset of the COVID-19 pandemic. Nearly 60% reported receiving no outside help during the shut-down; 65% endorsed feelings of abandonment, 60% being overwhelmed during the COVID-19 emergency. More than 60% endorsed significant life change, 35% increased conflicts with the PLWD, 65% concern about COVID-19 consequences for the PLWD, and 27% problems receiving consistent medical care. In logistic regression, PLWD prior-pandemic level of physical function (as reported as ability to leave the house with/without assistance) served as a protective factor for symptom change (odds ratio 0.20 [95% CI 0.00–0.29]).

DISCUSSION

The purpose of this study was to increase understanding of the influence of the COVID-19 pandemic

Table 2
Clinical information

	Total (n = 113)
Disease duration (y, mean, SD)	5.94 (4.43)
Dementia type (freq, %)	
Alzheimer's disease	43 (45.7)
Lewy body	6 (6.4)
Vascular	22 (23.4)
Mixed	2 (2.1)
Early-onset	2 (2.1)
Frontotemporal	3 (3.2)
Unknown	16 (17)
Clinical Dementia Rating Stage (%)	
0.5	3
1	44
2	42
3	24
Symptom change	
Changes in cognition (Yes, %)	91 (81.3)
Changes in neuropsychiatric symptoms (Yes, %)	88 (77.9)
New neuropsychiatric symptoms (Yes, %)	82 (72.6)
Number of new neuropsychiatric symptoms (mean, SD)	2.04 (1.74)
Change in motor symptoms (Yes, %)	89 (80.2)
Need to change medication due to symptoms	
Yes (%)	68 (68.2)
Prior physical ability (yes, %)	
Leave home independently	43 (37)
Leave home accompanied	67 (57.8)
Cannot leave home	6 (5.2)
Disease progress faster during pandemic	
Yes (%)	65 (57.5)
Person living with dementia aware of pandemic	
Yes (%)	51 (45.1)
Partially (%)	44 (38.9)
No (%)	18 (15.9)

Table 3
Service availability

	Total (n = 110)
Hospitalization availability	
Yes (%)	71 (64)
Dementia services availability	
Yes (%)	32 (29.3)
Partially (%)	35 (32.1)
No (%)	42 (38.5)
Urgent dementia services for neuropsychiatric symptoms or cognition available	
Yes (%)	52 (48.6)
Semi-residential/residential services available	
Yes (%)	19 (18.1)

within the dementia community in the US. Our findings coincide with work by Canevelli et al. [20] that has suggested that the pandemic had profound impact on persons living with dementia and those who care for them. Despite the progressive nature of the disease, evidence increasingly suggests [21] a hastened cognitive decline during this period, as did our results with a mean of more than two new symptoms occurring within the relatively short public health emergency period and generally surpassing historical prognosis found in longitudinal studies [22]. It is also recognized that within a variable, progressive disease and in an observational study design, there may be additional variables that account for this numeric change beyond the public health emergency.

More nuanced information is coming to light regarding the increase in neuropsychiatric symptoms, in part, secondary to measures of physical and social isolation [23]. Pandemic-related isolation also seems to have hastened motor skill decline nationally [24], which is reflected in our US-based sample. As reported by Rainero et al. [19], we also found a signal of a protective mechanism in the pre-pandemic physical ability of the person living with dementia (as reported by the ability to leave the house with/without assistance) in preventing significant increases of neuropsychiatric symptoms, suggesting that there is nearly an 80% decrease in the odds of increased neuropsychiatric symptoms with heightened reported physical ability. The reported challenges of the healthcare system at large to provide hospitalization services, urgent and routine dementia services, and residential services signals a significant need to care for this growing community.

Caregiver compromise throughout the public health emergency was also notable and amplified. As shared in work by Greenberg et al. [13], isolation leads to higher-hour care which then leads to

increased levels of housework, and increased challenges in coordinating care within and outside of the home. This was reflected in our results, signaling barriers in access and receipt of care. Caregivers are then dually disadvantaged due to the need to isolate themselves and the person living with dementia to lessen the risk of transmission and mortality, while paying a high price in their own social, mental, and physical well-being.

Conclusion

While many have looked and planned beyond the COVID-19 pandemic, the impact on persons living with dementia and their caregivers was substantial in comparison to society at large. A marked public health and preventative role signals a timely opportunity for practitioners and scientists alike to fill the void and prepare for future public health emergencies and isolation periods for societies most vulnerable. There too are industrial and organizational roles to further support and prepare adult care service and resource centers for future public health emergencies, along with those providing resilience and respite services for caregivers of persons with dementia. For many of societies vulnerable, the pandemic is not over, nor is our work.

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CONFLICT OF INTEREST

The authors have no conflict of interest to support.

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