

# End-of-Life Experiences within a Dementia Support Program during the COVID-19 Pandemic

 University of Colorado  
Anschutz Medical Campus

Adreanne Brungardt, MM, MT-BC, Jessica Cassidy, LMSW,  
Hillary D. Lum, MD, PhD

Division of Geriatric Medicine, University of Colorado School of Medicine

## Background

- During the COVID-19 pandemic, persons with dementia (PWD) faced a higher risk of mortality compared to older adults without dementia and experienced significant disruptions to long term services and supports.
- Here, we describe the context and circumstances of deaths of PWD within a caregiver support program at University of California San Francisco, Ochsner Health, and UHealth Seniors Clinic.

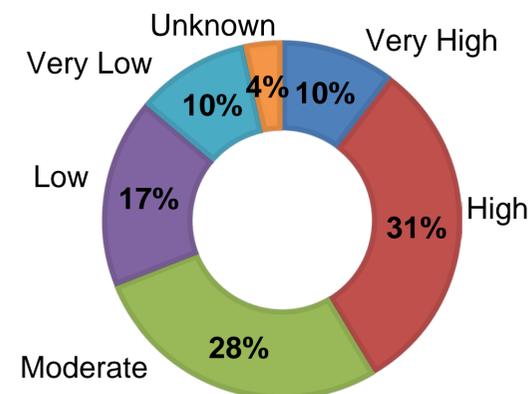
## Methods

- Retrospective data collection on decedents enrolled in a multidisciplinary team model for dementia care.
- Quantitative and qualitative data by chart review and input from clinic staff member assigned as regular point of contact for the care partner
- Data Collected: Demographics, end of life circumstances (if known), perceptions of potential impact of COVID-19 and/or social isolation on patients' end-of-life circumstances.
- Mixed methods analysis using descriptive measures and team-based thematic analysis

**Table 1. Decedents March 1, 2020 – February 28, 2021 (n=29)**

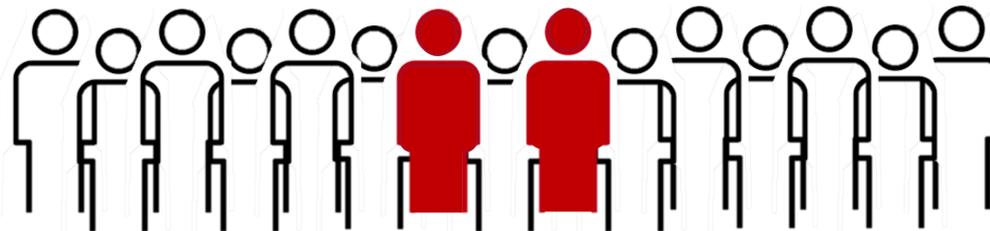
Characteristics	N (%)
<u>Age</u>	
60-69	3 (10%)
70-79	13 (45%)
80-88	8 (28%)
89 and older	5 (17%)
<u>Women</u>	12 (41%)
<u>Place of Living</u>	
Private Residence	18 (62%)
Assisted Living	6 (21%)
Nursing Home	5 (17%)
<u>Place of Death</u>	
Private Residence	13 (45%)
Assisted Living	5 (17%)
Nursing Home	5 (17%)
Hospital	2 (7%)
Hospice Facility	4 (14%)
Hospice Care	22 (76%)

**Figure 2. Impact of Social Isolation**



## Results

**Figure 1. There were known causes of death for 15 (53%) patients, two deaths were directly related to a COVID-19 infection. (in red)**



**Table 2. Qualitative Analysis**

Theme	Exemplar Quote
<b>Isolation Due to Pandemic</b>	Since mid-March this patient's spouse could not visit her in memory care and she became less mobile, lost the ability to sit up on her own and stopped eating. Prior to shelter-in-place restrictions, spouse visited 4-5 days a week and helped take patient for walks and fed her.
<b>Changes in Use of Dementia Support and Resources</b>	The caregiver was very overwhelmed and would've benefited from more hospice visits, but hospice reduced the number of visits due to COVID. It was difficult for her to find another caregiver during COVID as well.
<b>Impact on Goals of Care/Transitions of Care Decisions</b>	She was treated for a UTI and dehydration before being discharged home [from hospital] on hospice. Her spouse brought her home with 24/hour care so that they could be together, prior to hospital she was in memory care and they had not seen each other since mid-March.
<b>Communication Challenges for End-of-Life Care Coordination</b>	Spouse had difficulty making decisions for end of life care due to lack of communication from facility about how they were addressing COVID.

## Conclusions

- From the perspective of dementia caregiver support program staff, the COVID-19 pandemic had both direct and indirect influences on the context and circumstances of dying for persons with dementia.
- Care partners experiences of caring, decision making, and bereavement at end of life were affected by COVID-19.

## Implications

- By understanding how COVID-19 has impacted PWD and their caregivers' access to medical care, support services, and social environments, we may be better equipped to respond to the needs of these vulnerable dyads.

## Disclosures

The research reported on this poster was supported by Center for Medicare & Medicaid Innovation Comprehensive Primary Care Plus program. The investigators retained full independence in the conduct of this research.