

# End-of-Life Experiences Within a Dementia Support Program During COVID-19: Context and Circumstances Surrounding Death During the Pandemic

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## Abstract

**Background:** Persons with dementia (PWD) and their caregivers are uniquely impacted by the COVID-19 pandemic, including higher risk of mortality for PWD. **Objectives:** To describe the context and circumstances of deaths of PWD within a dementia support program during the COVID-19 pandemic. **Design:** Retrospective data collection of PWD deaths between March 1, 2020 and February 28, 2021. **Setting/Subjects:** Decedents enrolled in Care Ecosystem, a multidisciplinary team model for dementia care at University of California San Francisco, Ochsner Health, and UCHealth. **Measurements:** Using mixed methods, we analyzed data using descriptive measures and team-based thematic analysis to understand the end-of-life (EOL) experience of PWD-caregiver dyads. **Results:** Twenty-nine PWD died across three sites. Almost half (45%) were between ages 70-79 and 12 (41%) were women. Eighteen (62%) died at a private residence; two died in the hospital. Hospice was involved for 22 (76%) patients. There were known causes of death for 15 (53%) patients. Only two deaths were directly related to COVID-19 infection. Social isolation was perceived to have a high or very high impact for 12 (41%) decedents. Four qualitative themes were identified: (1) isolation due to the pandemic, (2) changes in use of dementia supports and resources, (3) impact on goals of care decisions, and (4) communication challenges for EOL care coordination. **Conclusion:** Among PWD and caregivers enrolled in a dementia support program, the COVID-19 pandemic had direct and indirect influences on mortality and EOL experiences of PWD. Caregivers' experiences of caring, decision making, and bereavement were also affected.

## Keywords

dementia care, caregiver, support program, end of life, COVID-19, pandemic

## Introduction

Older adults have been uniquely and adversely affected by COVID-19 compared to younger populations.<sup>1</sup> Beyond increased vulnerabilities from age alone, COVID-19 also disproportionately affects persons with dementia (PWD).<sup>2</sup> Approximately 11% of U.S. older adults aged 65 and older have Alzheimer's disease and related dementias, with 6.5 million Americans currently living with the disease.<sup>3</sup> PWD are at increased risk of infection and spreading COVID-19 due to cognitive limitations and behavioral symptoms that may prevent their ability to follow social distancing protocols.<sup>4</sup> PWD are also disproportionately hospitalized for COVID-19, experiencing increased risk of complications and mortality compared with younger adults and older adults without dementia.<sup>1,5</sup>

Emerging literature indicates a high prevalence of dementia among persons who died from COVID-19.<sup>2,6,7</sup> Zuin et al

(2020) evaluated eight articles (N = 6493; mean age 69.6 years) in a systematic review and meta-analysis, finding one of every four COVID-19-related deaths were PWD. Notably, the Alzheimer's Association (2022) reported deaths due to Alzheimer's disease and other dementias increased

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17% during the first year of the COVID-19 pandemic. These excess deaths have been attributed to both the direct and indirect (eg, lockdown) effects of the pandemic.<sup>8</sup>

In addition to direct and indirect risks of mortality due to COVID-19, PWD and their family caregivers experienced unique challenges. Significant disruptions of long-term services and supports occurred due to the pandemic.<sup>9</sup> Caregivers of PWD needed to adjust quickly to changes in availability of community-based resources and/or home health care.<sup>10</sup> High COVID-19 infection rates and associated restrictions may have influenced how PWD and their caregivers navigated end-of-life (EOL) goals of care decisions and care transitions. In the context of social distancing requirements, many PWD-caregiver dyads may have also experienced increased social isolation.

Recognizing the vulnerabilities of PWD and their caregivers, healthcare systems have increasingly implemented evidence-based dementia support programs for PWD and their caregivers.<sup>11</sup> Care Ecosystem (CE) is a multidisciplinary team model for dementia care.<sup>12</sup> Within the model, PWD and a family caregiver are enrolled as dyads in a longitudinal program that provides education, caregiver support and coordination of care primarily through monthly contact with a trained dementia Care Team Navigator (CTN).<sup>13</sup> Because the CTNs provide longitudinal support to PWD-caregiver dyads, they are uniquely well-suited to describe the context and circumstances surrounding the EOL experiences of PWD and caregivers including the impact of the pandemic on these experiences. In a cohort of PWD who died during the first year of the COVID-19 pandemic, we explored place, cause of death (if known), and perception of whether COVID-19 contributed to death. We also sought to understand the potential effect of COVID-19 pandemic changes and social isolation on the EOL experiences of PWD.

## Methods

### Study Design and Participants

This is a retrospective cohort study of decedents who were enrolled in CE programs at University of California San Francisco (UCSF), San Francisco, CA; Ochsner Health, New Orleans, LA; and UCHealth Seniors Clinic, Aurora, CO. CTNs associated with the decedent were asked to complete one data collection tool per PWD who was enrolled at the time of their death between March 1, 2020 and February 28, 2021. A data sharing agreement between all three institutions was executed. No protected health information was shared. Institutional Review Board approval was not required.

### Setting

At UCSF, CE is implemented in a research setting where PWD are enrolled throughout the state of California and receive care from a centralized hub. In addition, it is implemented in the

UCSF Memory and Aging Center clinic where care is coordinated with neurology care. In March 2020 there were 115 active dyads.

Ochsner established CE as a research study in February 2019. Referrals come from a variety of sources including outpatient neurology clinic, a multi-disciplinary memory clinic, primary care, and community referrals. Dyads are enrolled for one year with two full-time CTNs each serving an average of 60 active dyads at a time.

At UCHealth, an adaptation of CE is implemented as the Living with Dementia program in UCHealth Seniors Clinic. The clinic serves approximately 2800 patients with an average age of 84 years. The adaptation launched in September 2018 and serves an average of 50 dyads with staffing by two part-time CTNs.

### Data Collection

The topics and questions were developed by the multi-site authorship team and discussion with a larger, multidisciplinary group of collaborators with experience implementing the CE model and awareness of how the COVID-19 pandemic might be affecting the EOL experiences of PWD-caregiver dyads. A data collection tool was created using REDCap (Research Electronic Data Capture, Nashville, TN). CTNs completed the data collection tool by reviewing the electronic health record, including clinical documentation notes and/or separate program documentation. The tool was used to assess decedent demographics (eg, age in deciles, gender, race, ethnicity), circumstances prior to death, and EOL experiences. The tool collected discrete data and free text descriptions for CTNs to describe their perceptions on the context and circumstances surrounding the death ([Supplementary Material A](#)).

### Analysis

In a sequential mixed methods approach, we first analyzed the quantitative data using descriptive measures. Then, qualitative analysis of the free text responses was guided by the RADaR (Rigorous and Accelerated Data Reduction) method.<sup>14</sup> Completed in five steps, we began by formatting and organizing the data for semblance. Next, we created a phase one data reduction table by copying and pasting all qualitative data into a Microsoft Excel spreadsheet. Two coders (A.B. and J.C.) then individually reviewed the data and made notes of commonalities and differences. Next, the researchers compared notes and came to consensus regarding the guiding research questions. Qualitative data irrelevant to the research questions was then eliminated to produce the phase two data table. Following this, the researchers worked independently to develop open codes and then came together to reach consensus and develop “focused codes”.<sup>15</sup> Lastly, an iterative process was applied until the coded data was reduced to produce the final themes. Given the small number of decedents, participant

characteristics are not described as part of the qualitative data so that participant identity is not inadvertently disclosed. The quantitative and qualitative data were integrated in the interpretation and discussion of study findings.

## Results

Across three geographic sites, 29 PWD died while enrolled in Care Ecosystem between March 1, 2020 and February 28, 2021 (Table 1). Almost half (45%) were between ages 70 and 79 and 12 (41%) were women. The majority of caregivers were spouses (72%) and prior to death, 15 (52%) patients were living with their family caregiver. Eighteen (62%) died at a private residence and two died in the hospital. Hospice was involved for 22 (76%) patients at time of death.

Cause of death was documented in the EHR for 15 (52%) patients. Two deaths were directly related to a COVID-19 infection. Death was perceived to be sudden or unexpected for 10 (35%) patients. CTNs reported COVID-19 influenced a third (33%) of the families' decision making related to care. The frequency of whether COVID-19 was thought to have indirectly contributed to the cause of death from the CTN perspective was as follows: 2 definite contribution, 3 probable, 12 possible, 8 no contribution, and 4 unable to answer. Social isolation was perceived to have a high or very high impact on the dyad during EOL for 12 (41%) decedents.

Four qualitative themes and five subthemes were identified related to influence of the COVID-19 pandemic on the care and EOL experiences of PWD: (1) isolation due to pandemic, (2) changes in use of dementia supports and resources, (3) impact on goals of care decisions, and (4) communication challenges for EOL care coordination.

**Table 1.** Persons With Dementia Who Died During the COVID-19 Pandemic (March 1, 2020-February 28, 2021), N = 29.

Characteristics	N (%)
Age	
60-69	3 (10)
70-79	13 (45)
80-88	8 (28)
89 and older	5 (17)
Women	12 (41)
Place of living	
Private residence	18 (62)
Assisted living	6 (21)
Nursing home	5 (17)
Place of death	
Private residence	13 (45)
Assisted living	5 (17)
Nursing home	5 (17)
Hospital	2 (7)
Hospice facility	4 (14)
Use of hospice care	22 (76)

### Theme 1: Isolation Due to Pandemic

With varying levels of social distancing and shelter-in-place policies, distinctive periods of isolation occurred during COVID-19. As observed by CTNs, increased isolation uniquely influenced PWDs, the dyad as a unit, and caregivers. Additionally, isolation seemed to have varying effects prior to death, during the dying process, and following the PWD's death.

**Functional Decline Prior to Death.** CTNs described caregivers' perceptions of the PWD's decline or accelerated decline in tandem with increased levels of isolation.

Since mid-March [2020], this patient's spouse could not visit her in memory care and [PWD] 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.

Social isolation [caused PWD] not [to be] able to go to the gym; functional and cognitive decline occurred rapidly.

**Physical Separation During Final Days of Life.** CTNs described how dyads experienced visitation restrictions at facilities or hospitals during the PWD's last days. This separation was reported by CTNs to have a significant impact on their dyads.

Caregiver used to visit regularly but with the lockdown he was only able to see patient through a fence outside. [It was] extremely difficult for caregiver to not be with patient in the advanced stage and during the time leading up to her death. [It was] difficult to observe the decline from a distance without being there in person.

**Limited Socialization During Bereavement Period.** After the PWD died, some caregivers experienced unique isolation during bereavement as a consequence of family not being able to be present at time of death, during the funeral, or during the grieving process. Funeral arrangements often had to be modified due to travel restrictions and physical gathering limits.

Their daughter couldn't be with them in person at the time of death. The caregiver [spouse] was all alone with patient shortly before death and after his passing, which was very emotionally difficult and isolating. They weren't able to hold any service or memorial.

Son and grandkids were only able to see caregiver at a distance after patient passed away, it was very isolating for caregiver. Son was able to FaceTime patient in the hours leading up to death. Caregiver had other friends and family but no one was able to come by in person. There was no service held. It was difficult for her because she's a very social person and patient was a respected member of their community and not being able to come together to grieve or hold a celebration of life was very difficult.

## **Theme 2: Changes in Use of Dementia Support and Resources**

Access and usage of dementia support resources were altered or interrupted for many of the dyads. Changes in use of dementia support and resources related to both decisions made by caregivers to reduce COVID-19 exposure and community/health system-level issues including service closures, changes or shortages in staff, policies, and state and county mandates.

**Caregiver Preferences.** Some changes in dementia supports stemmed from caregiver decisions including modifications to or removal of in-home support personnel due to COVID-19 exposure concern despite availability.

Caregiver decided to fire two of her long-time paid caregivers due to Covid concerns... and [subsequently] hire a new one.

The couple was more isolated than they would have [been] without the pandemic. They had the help of one person very part-time but the wife caregiver didn't want others coming into the home.

**Limitations of Available External Services.** All three CE programs experienced national, state, and county mandates and guidelines for public safety because of the pandemic. Severity and length of mandates and guidelines varied between and within locations. These external measures altered access and availability of dementia supports and caregiver respite including adult day care, non-skilled home health agencies, community senior programming, travel, and social engagements.

The caregiver was very overwhelmed and would've benefited from more hospice visits, but hospice reduced the number of visits due to COVID-19. It was difficult for her to find another caregiver during COVID-19 as well.

Wife noted that in May 2020 facility had administration and staff changes to almost an entirely new staff. Wife felt quality of care suffered. Patient started having falls and was admitted to the hospital with severe kidney and bladder infection.

## **Theme 3: Impact on Goals of Care or Transitions of Care Decisions**

Both goals of care and transitions of care decisions were influenced by the COVID-19 pandemic, including decisions related to treatments of medical issues and discharge after hospitalization.

She was treated for a urinary tract infection 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 hospitalization, she was in memory care and they had not seen each other since mid-March.

Spouse did not want to pursue evaluation and treatment for suspected stroke due to possible exposure to COVID. She also felt that extensive testing would be invasive and that if [PWD] were able to make decisions for end of life care he would prefer to be comfortable and minimize medical interventions.

## **Theme 4: Communication Challenges for End-of-Life Care Coordination**

CTNs noted that caregiver communication with care teams (ie, hospital, nursing facility, hospice agencies) and coordination of discharge planning was complicated.

Spouse had difficulty making decisions for end of life care due to lack of communication from facility about how they were addressing COVID.

Spouse had difficulty getting a response from hospice agency when needed.

Collectively, the themes indicate greater levels of distress experienced by caregivers as they were often isolated from their PWD during the EOL stage and bereavement, had significant difficulties securing needed supports due to social distancing protocols and widespread staff shortages, and encountered unique challenges in coordinating care and making decisions related to goals of care.

## **Discussion**

This study describes the context and circumstances of EOL experiences of 29 PWD through the lens of dementia support program staff embedded in healthcare systems. Our results highlight the multiple ways the COVID-19 pandemic impacted EOL circumstances of PWD even without direct infection with SARS-CoV-2 itself.

Only two decedents died directly from COVID-19 infection and 8 (28%) of the contexts of deaths were reported to not be related to COVID-19 at all. This may reflect that dementia remains a terminal illness even in the absence of a global pandemic. Still, without direct infection, CTNs attributed at least a possible indirect influence to cause of death for 17 (59%) decedents, mainly due to PWDs' decline during increased isolation and/or change of supports. Public health measures aimed to slow the spread of the virus had profound implications.<sup>9,16,17</sup> Additionally, our data found that even when services were reinstated and available, caregivers still chose to modify or remove home care personnel from coming into their home. For these dyads, the risk of contracting the virus outweighed the benefits of the service.

In this study we found isolation occurred at three distinct time points. Prior to death, isolation was due to change of support services and public health orders. This compounded the pre-existing prevalence of social isolation for PWD-caregiver dyads even prior to the COVID-19 pandemic.<sup>18,19</sup>

Secondly, isolation during EOL stages was distinct, especially when PWD and caregiver were separated due to residential facility policies or hospitalization. Lastly, unique to the pandemic, isolation for bereaved caregivers was common following the PWD's death.

For PWDs within a residential facility during a pandemic, this study highlights increased risks of decline from lack of support previously met by visitors and staffing shortages affecting residential care of PWD. CTNs noted communication and coordination of care between caregivers and the long term care facility was difficult during the pandemic. Our data highlights the challenges of residential restrictions for family caregivers, influencing whether or not to have their PWD return to a facility after hospitalization, as well as experiencing their own isolation of having to watch the PWD decline from afar.

Interestingly, the impact of COVID-19 on hospitals and residential facilities may or may not have affected the PWDs' preferences related to EOL care. Only 2 out of 29 patients died in the hospital. Appointed family decision makers of PWD living at home or in nursing homes often choose comfort care for their loved one<sup>20,21</sup> however, concordance between advance directives and a decision maker's preference for level of care does not always align.<sup>22</sup> In our cohort of PWD, some caregivers chose not to pursue invasive treatments and chose for the PWD to not die in a hospital. CTNs described how goals of care decisions or care transitions reflected pandemic-related concerns such as visitation restrictions or increased exposure risk rather than previously discussed goals of care discussions or advance directives.

This study had several limitations. The data are from a clinical team respondent and not the family caregiver. Specific to whether the PWD's death was directly or indirectly impacted by COVID-19, there are two sources of uncertainty: (1) uncertainty from the caregiver regarding whether the decedents were exhibiting symptoms of COVID-19 infection, exposed to those positive for COVID-19 (especially when community-based testing was scarce), or observing an accelerated decline during the pandemic-related lockdown; and (2) uncertainty from the CTN respondent of their second-hand knowledge of the dyads' situation. Secondly, for 2 decedents the primary CTN was no longer available and another team member completed the data collection tool based on note review alone. Also, this is a small cohort and not generalizable. Further work should be expanded to a larger qualitative and potentially quantitative study that includes additional Care Ecosystems or other dementia caregiver support programs.

For PWD and their family caregivers, the context of medical and social changes due to the COVID-19 pandemic can inform how healthcare teams, dementia caregiver support programs, and community-based dementia care services prepare for and coordinate care as part of long-term services and support, hospitalizations and care transitions, EOL and bereavement periods that occur during pandemics and potentially other public health emergencies. This study informs

how dementia care programs such as Care Ecosystem can tailor and broaden care protocols to include specific information and address COVID-19 related needs for improved communication, care coordination and support targeted toward social isolation.<sup>23</sup>

From the perspective of dementia caregiver support program staff, the COVID-19 pandemic had both direct and indirect influences on the context and EOL circumstances of PWD including how caregivers experienced caring, decision making, and bereavement.

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### Author Contributions

All authors contributed to the design, acquisition, analysis, and/or interpretation of the data with substantial revisions to the final version for publication.

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### Disclaimer

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### Supplemental Material

Supplemental material for this article is available online.

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