

[COVID Information Commons \(CIC\) Research Lightning Talk](#)

[Transcript of a Presentation by Amanda Leggett \(University of Michigan\), November 15, 2021](#)



Title: Caregiving on the Frontline: Caring for an Individual Living with Dementia during the COVID-19 Pandemic

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Transcript

Amanda Leggett:

*Slide 1*

Okay hi and good afternoon at least on eastern time zone everyone. It's my pleasure to be here today and share some of the early findings from my work on caregiving during COVID-19 specifically caregiving for an individual living with dementia during the pandemic.

*Slide 2*

And I would first like to start by acknowledging my funding for this work, which comes from my career development award from the National Institute on Aging and a supplement to that award specific to COVID-19. I have a fabulous research team and also mentor collaborators who have supported this work.

*Slide 3*

So first, to start out about the COVID context which I'm sure is familiar to everyone but specific to caregiving and aging. So, we know from existing work on natural disasters that older adults, especially those with pre-existing medical conditions, are at increased risk for negative effects from such global crises. And specifics of COVID-19, we've seen that older age is related to critical health outcomes as well as mortality specific to COVID-19, which really puts older adults and individuals with dementia specifically and their care partners at an increased risk for negative outcomes to COVID-19. Also, throughout the pandemic, we've seen how healthcare systems have shifted to really have a singular

focus on COVID, leaving fewer resources for other medical conditions which may be very common among older adults. And so, there's been a little bit more of a struggle to potentially get ordinary or routine care. So, for a variety of reasons the pandemic may be acting as a barrier to caregiving due to this ongoing fear of infection for both the caregiver and the individual [with] dementia for whom they're providing care.

#### *Slide 4*

Also, we've seen changing policies during the pandemic that have impacted older adults' individuals with dementia, and their caregivers. So, caregivers may be asking themselves the question should I abide by physical distancing regulations or do I continue to provide essential care to my friend or relative? We've seen restrictions on typical daily activities, reduced physical activity as an association of physical distancing orders, and older adults have lost many outlets such as respite programs or churches or even restaurants. We don't often think about that, but just the social interaction and the chance to take a break from care that going out to eat can provide is enormous for many individuals with dementia and their caregivers. And caregivers have had a greater difficulty in accessing services and healthcare and may have had to shift to relying on services and new modalities such as telehealth. All these dramatically changing the caregiving landscape.

#### *Slide 5*

So, my research has focused on primary family caregivers for an individual living with dementia during the pandemic. We've done mixed methods interviews, and today I'll be sharing some findings some emerging findings on a preliminary sample of our participants. We have just finished wrapping up recruitment for this study. And the individuals living with dementia were community dwelling, so not in a nursing home or assisted living care facility, and they were not at the terminal stage of disease.

#### *Slide 6*

Here's just a little bit about our sample. On average our caregivers were in their mid-60s. The majority were married. We, being at the University of Michigan in a college town, we have a pretty highly educated sample and you can see the diversity by race there.

#### *Slide 7*

So, starting out, how did the pandemic impact caregivers' lives, according to them? So, on the left chart you can see we asked caregivers to talk about whether the pandemic impacted their ability to participate in activities that gave them that break, that gave them respite from care. And you can see that the majority said that they did experience impact on those activities with about half the sample saying quite a bit or extreme impact. Then on the right-hand side, at first this chart may seem encouraging that you know over half of the sample said they had no financial difficulties that made

caregiving more difficult. But on the flip side, you can see about half the sample did report financial difficulties making their caregiving lives more challenging.

#### *Slide 8*

We also asked about the impact on their relationship with the individual with dementia, and you can see again over half said that their relationship stress increased both at a moderate or severe level during the pandemic. And then we ask about their ability to provide care kind of relating to caregiving stress. Was it easier or more difficult to provide care during a pandemic? And you can see that about half of the sample said it was somewhat to extremely difficult to provide this care.

#### *Slide 9*

We also looked at a variety of challenges and also supports that caregivers could report experiencing during the pandemic, and these were actually items that we created for the national poll on healthy aging which is sponsored by the AARP and the Michigan Medicine. And this left-hand column is that national poll sample and we've published those findings you can see in the upper left-hand side. So, the national pole sample specifically looked at caregivers for any adult age 18 and older with any chronic illness or disability, whereas our right-hand column is our dementia caregiving sample. And you can see that universally, the dementia caregivers reported greater experiences of these caregiving challenges such as difficulty getting medical care for one's care recipient or providing less care to reduce risk of spread or you can see over half of the samples said they received less support from family and friends in assisting with care during the pandemic. I want to hone in a little bit on these top two challenges of getting needed in-home and out-of-home services and in getting needed medical care.

#### *Slide 10*

So specifically, we asked caregivers what sorts of services they had greater difficulty in accessing? And again, similarly there you can see that about half of the sample said they had greater difficulty getting respite from family or friends, and you can see nearly half of our samples said they had difficulty getting regular medical care such as physician appointments, with day activity programs also almost nearing half of our sample.

#### *Slide 11*

Because this was a mixed method study we also did in-depth interviews with the caregivers, and these issues of medical care and community-based services came up again and again. So, I thought I would quickly share with you some striking quotes that we've seen from these interviews. So first here the difficulty of just getting a medical appointment during the pandemic. You can see the caregiver said they had to reschedule or cancel an appointment because the individual with dementia didn't want to go, and this can be a common challenge with dementia. And then the caregiver said it was very difficult to then get another appointment because the wait times were so long and the caregiver really had to

advocate for that appointment. A complimentary issue is that often caregivers were not allowed in appointments during the pandemic with only the patient being allowed in, but when it comes to dementia this is very difficult because they may not be able to relay an adequate history or adequately describe the symptoms or what they're experiencing. And so, you can see this caregiver saying they weren't allowed back at first which was a problem, and they felt embarrassed somewhat to try and have to explain to the care provider why they needed to be back there because they didn't want the individual with dementia to feel ashamed.

#### *Slide 12*

They also talked about difficulty getting respite services and the community and to their home having long wait times or people being scheduled to come who would just never show up. And then of course telehealth, which has become a new thing for many of us throughout the pandemic. Caregivers had really mixed experiences with that, some citing great benefit of not having to leave the home for appointments, but you can see with this caregiver here saying you know some were helpful and some were a total waste of time, that they felt the doctor really needed to see the individual with dementia in person. And then finally just getting comfortable and managing the technology to have telehealth appointments was a new challenge especially for older adults and individuals with dementia. Here you see the caregiver describing that the gentleman on the phone was trying to help the individual with dementia get set up for that telehealth appointment and just really you know belittling the individual dementia for not knowing how to use a computer, and so the individual with dementia ended up feeling ashamed.

#### *Slide 13*

So, in conclusion, there's I think many implications here, but older adults living with dementia are very complex patients. They have multiple comorbidities often that makes their care management very challenging, particularly in a pandemic context. And so, when handling care, I think one of the recommendations I would put forth is that health systems really need to consider the role of caregivers in patient healthcare and making sure that they have plans for how they can safely involve caregivers in these appointments and in future care planning.

#### *Slide 14*

So, thank you so much for attending today and of course, much gratitude to my participants who gave of their time during a crazy pandemic to share their stories with me. Thank you.