Caregiving and Advance Care Planning During the COVID-19 Pandemic

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Key Messages: Some (19%) of family caregivers revisited or updated advance directives of care-recipients and/or had some type of contingency plan (33%) if they were to become ill. We identified three barriers caregivers faced during the pandemic that may have limited their engagement with ACP. Family caregivers need education regarding ACP and specific resources that can guide and support them through the process of ACP, both for themselves and care-recipients.

Background
- 53 million Americans provide informal care for family or others who are chronically ill, aging, or disabled.1
- Care includes medical, emotional, financial, and legal support.2,3
- High quality end-of-life care necessitates engaging in communication and documentation of the patient’s goals, values, and preferences (i.e., advance care planning: ACP).
- Little is known regarding the influence of the COVID-19 pandemic on ACP in community-based caregivers and care-recipients

Purpose
Explore the experiences of caregiving dyads in ACP during the COVID-19 pandemic.

Methods
Design: Exploratory sequential mixed-methods
Participants: community-based caregivers of care-recipients of any age and with any care needs (e.g., autism, dementia, mental illness).
Data collection: July - September of 2020.
Measures: Quantitative surveys & qualitative semi-structured interviews included caregiver access to resources (e.g., respite), social isolation, stress, and coping.
Qualitative interviews explored topics in depth, with a sub-sample of participants.

Key Domains Related to Advance Care Planning

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<th>Barrier</th>
<th>Context</th>
<th>Exemplar Quote</th>
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<td>Interruption of Care Plans (changes to meals plans, day care, transportation, etc.)</td>
<td>A woman who is the primary caregiver for her husband with dementia, needed to have hip surgery.</td>
<td>...well, it was probably about two months into the pandemic I had to have a hip surgery... in addition to trying to take care of my husband, who has Alzheimer’s... for the last month we've been trying to get him placed into a home, and it's just been hard because we've had to rely on a lot of other people, all my kids and my neighbors... we had him an adult daycare to start going to a couple times a week, and he went once, and then the pandemic shut everything down, so then there was no place that I could turn to that I could have him go to...</td>
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<td>Focus on the Present (demanding day-to-day care needs prevent future planning)</td>
<td>A woman caring for her husband with dementia is focused on her husband’s day-to-day needs.</td>
<td>Well, I guess I don’t really look too far in the future. At some point, my husband’s probably going to need home health care, or hospice care... Focus on the day to day; I guess, with COVID, I have to keep a little bit of a closer watch on him. If the doorbell rings, he’ll go to the doorbell and forget that he shouldn’t answer the door or let people in, so a greater watch with it. I monitor his health really closely. I nudge him a lot more about using the walker.</td>
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<td>Navigating with a Compass (lack of knowledge or resources related to ACP)</td>
<td>A woman caring for her husband discussed how COVID-19 hasn’t urged them to complete an advance directive.</td>
<td>No. I don’t think it’s occurred to us, to [complete an advance directive]. I think we’re just hoping for the best possible outcome. And, you know, compared to where we were in February and the first part of March, where everybody was just stopped, terrified, because there weren’t any treatments, I think we’ve all seen so many people recover, and we’ve seen so many variations of what the illness is for so many people, that we’re just hoping that we would get to be in the we’ve got good genes category... Hope for the best.</td>
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Results
Caregivers (N=82) were primarily female (85%), White (94%), and had at least a college education (74%). 53% of caregivers provided 20+ hrs. of care per week. 63% participants reported that the care-recipient had a completed advance directive (19%) reported that it has been updated since the start of the pandemic. One-third of caregivers had contingency plans in the event that they were to become sick.

Conclusions
Although the pandemic has been touted as an opportunity to elevate the importance of ACP, it may not have only resulted in incremental increases of ACP engagement among family caregivers. The identified barriers to ACP can be addressed by providing specific education and tools to guide caregivers through the process of ACP to help achieve end of life experiences that align with the care-recipients values, preferences, and goals for care.

References