

Spousal dementia caregivers' use of technology during the COVID-19 global pandemic: Lessons learned from the NYU family support program

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Abstract

Background: Daily routines have been drastically impacted by COVID-19, including healthcare appointments, home services, and many recreational opportunities. Spousal dementia caregivers (CGs) are particularly vulnerable during COVID-19, as many rely on family members, daycare, in-home assistance, and other respite opportunities. We conducted qualitative interviews in May/June 2020 to understand the impact of COVID-19 on dementia CGs and how they experienced the switch of all the NYU ADRD Family Support Program (FSP) services to telehealth.

Method: A total of 10 spousal CGs participated in videoconference interviews about their COVID-19 experiences and the FSP's transition to the telehealth format. Semi-structured interviews were conducted by one of two interviewers who were external to the FSP to encourage freedom of discussion. All sessions were recorded and transcribed. De-identified transcripts were coded by two independent coders using NVivo, with discrepancies resolved by a third researcher.

Result: CGs ranged in age from 54 to 86; 7 were female, 8 were non-Hispanic White, and 2 were Black. All were New York City residents living with the person with dementia; 2 households had additional adult family members. Qualitative analysis revealed several major themes related to COVID-19 experiences: fears surrounding COVID-19 and staying healthy; changes in daily routines; the impact of reduced respite and support services; adaptation to technology that enabled increased contact with family/friends. Feedback about the telehealth adaptation of the FSP included observations about new group dynamics and decreased barriers to involvement due to the ability to participate from home, reducing the need for transportation and other logistics related to traveling.

Conclusion: Despite significant challenges due to COVID-19, CGs reported benefit and support from the FSP in the new telehealth format. One participant described the FSP as "indispensable" and expressed how much members relied on each other during COVID-19. In addition, we learned that the telehealth FSP not only served as a source of support during the crisis but that there were perceived advantages to this

format, including reductions in barriers to in-person services (finding transportation, travel time, getting respite care for the person with dementia). We recommend continuing the option of telehealth services for dementia CGs after the COVID-19 crisis.