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Regular Research Article

Telehealth Support for Dementia Caregivers During the COVID-19 Pandemic: Lessons Learned From the NYU Family Support Program

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ABSTRACT

Objectives: In response to the needs of dementia caregivers during the COVID-19 pandemic, the NYU Langone Alzheimer's Disease and Related Disorders Family Support Program (FSP) quickly transitioned to providing most services online. To understand how dementia caregivers experienced FSP services after the switch to video telehealth, we conducted qualitative interviews of spouse or partner dementia caregivers. **Participants:** Ten participants were recruited from a convenience sample of dementia spouse or partner caregivers who used one or more online FSP services offered during the pandemic. **Design:** Caregivers engaged in semi-structured interviews held via videoconference between May and June 2020. Qualitative analysis of interviews was conducted according to the principles of framework analysis. **Results:** Caregivers reported high satisfaction with the FSP pre-pandemic and continued to feel supported when services were provided online. They transitioned to video telehealth services with little difficulty. **Conclusions:** While video telehealth is frequently cited as beneficial for those in rural communities, socioeconomically disadvantaged groups, or homebound individuals, our findings suggest that video telehealth is also advantageous for dementia caregivers, given their unique barriers, including lack of time due to caregiving responsibilities, lack of respite care for the person with dementia, and the additional burdens of travel time to access in-person services. (Am J Geriatr Psychiatry 2023; 31:14–21)

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Highlights

- **What is the primary question addressed by this study?**

The primary purpose of this study is to understand how dementia caregivers experienced online support services after switching to videoconferencing during the COVID-19 pandemic.

- **What is the main finding of this study?**

We found that dementia caregivers had high satisfaction with pre-pandemic services and continued to feel supported by services provided online. They also transitioned to telehealth services with little difficulty.

- **What is the meaning of the finding?**

Dementia caregivers are able to utilize and benefit from telehealth support services, and our findings suggest that telehealth is an advantageous means of securing support services during the pandemic and moving forward.

INTRODUCTION

New York City was an early epicenter of the coronavirus disease pandemic (COVID-19) during the spring of 2020.¹ Among those hardest hit in the initial wave of infections were older adults with underlying medical conditions, who faced the strictest restrictions under the statewide stay-at-home order which, though intended to protect them, left millions isolated with limited or no access to friends, family, and medical and supportive services. These protective measures also reduced or eliminated access to the formal and informal support for most dementia caregivers^{2–4} that is essential to their well-being.^{5–13}

Results of multiple randomized controlled trials of the NYU Caregiver Intervention, which were influential in funding of caregiver support programs throughout New York State, including the FSP, demonstrated that caregivers who receive emotional and practical support experience less depression and stress, and better physical health, and are thereby able to keep their relatives with dementia at home longer than those who do not have the benefit of such support.^{14–16}

Early studies on the impact of COVID-19 on dementia caregivers have shown that removal of previously available programming and social supports significantly increased caregiver workload and stress.^{17–19} As caregiving demands increased and access to resources decreased, caregivers took on new roles that they felt inadequately trained to carry out.^{2,20,21} During the pandemic, nearly half of

caregivers reported role overload⁴ and insufficient availability of support services.^{4,19} In contrast, those who felt supported by family and friends were able to recognize positive aspects of caregiving.^{4,22}

The pandemic forced health care providers to quickly convert most visits to a telehealth modality and limiting face-to-face visits to continue providing care while maintaining safety. Though there was some apprehension about the usability of video telehealth with older adults due to concerns about technological literacy, research has shown that older adults are interested in learning about new technology and are willing and able to adopt new technology,^{23,24} with no difference in satisfaction ratings between telehealth and in-person settings.^{25,26} Multiple recent studies suggest high satisfaction with care and no detriment to the patient-provider relationship among older adults using telehealth.

There was a call for a digital revolution driven by the need for telehealth services for dementia caregivers during the pandemic.²⁷ Further, a scoping review of the experiences of people living with dementia and their caregivers during COVID-19²⁸ identified an urgent need for research on home-based interventions.

The NYU Langone Alzheimer's Disease and Related Disorders Family Support Program (FSP), directed by Mary S. Mittelman, DrPH, has been supported by a New York State Department of Health grant since 2016. Until the pandemic, FSP services were provided mostly in person, although consultation was also available by phone or videoconferencing. Due to the pandemic, in mid-March 2020, the FSP stopped all in-person services and immediately

began offering all but one program (one linking students to people in the early stages of dementia) via video telehealth. Since the transition, program staff have daily team meetings via videoconferencing to maintain team cohesion and exchange information. In the year prior to the pandemic (March 15, 2019, to March 14, 2020) the FSP served 721 participants. In the first year of the pandemic, following transition to video telehealth services (from March 15, 2020, to March 14, 2021) the FSP served 676 participants. As part of efforts to assure quality of services was maintained after the transition from in-person to online services, and to understand the impact of the pandemic on dementia caregivers, qualitative interviews of a sample of older adult spouse or partner caregivers were conducted.

METHODS

Participants

Ten participants were recruited from a convenience sample of spousal or partner caregivers participating in one or more online services offered by the FSP during the pandemic. Caregivers were contacted by FSP staff and invited to participate in semi-structured interviews via videoconference between May 22 and June 17, 2020. To be included, caregivers had to reside with the person with dementia (PWD), identify as the primary caregiver, have internet access, and agree to have the interview recorded. A total of 7 female and 3 male caregivers, ages 55 to 86, participated. Nine were non-Hispanic White, and one was Black. Participants' primary residence at the start of the pandemic was NYC. One couple had moved to a second home outside the city, and one was spending weekends in their second home.

Procedures

Two interviewers (MKO and TD) unaffiliated with the FSP conducted semi-structured interviews via videoconferencing. Participants verbally consented to have the interview recorded. Demographic details were collected first, followed by open-ended questions about the pandemic and the experience of the FSP pre-pandemic and during the pandemic. See Appendix for interview questions. All interviews were conducted in English and recorded via WebEx,

transcribed using InqScribe software, and de-identified. This project was designed as a quality improvement effort and deemed exempt from IRB review.

Qualitative analysis was conducted according to the principles of framework analysis²⁹ using the following stages: familiarization with the corpus of interviews; initial coding; creation of a codebook and broader analytic framework; application of the codebook to the entire corpus of interview data; charting the coded data into a framework matrix; and interpretation of coded data. Upon receipt of de-identified transcripts, the qualitative specialist, in collaboration with the project team, produced a codebook consisting of codes related to *a priori* areas of interest and involved inductive analysis to identify novel, unanticipated codes. Upon final review and team agreement on the codebook, the team's two coders were trained on the codebook and qualitative analysis software NVivo 1.4 for Windows. Once a satisfactory agreement was achieved from coding a subset of the interview corpus, the entire corpus of interviews was coded. Coding discrepancies were resolved by the codebook creator in consultation with coders to arrive at the finalized coding. Data was then charted into a framework matrix that was shared with the project team to guide interpretation.

RESULTS

Examination of qualitative data revealed thematic saturation with our sample of 10 participants.^{30,31} The overarching thematic areas identified through qualitative analysis fall into two broad categories. The first theme relates to the general experiences of caregivers during the pandemic. The second specifically relates to caregivers' utilization and satisfaction with the FSP's video telehealth services and the use of technology adopted by caregivers during the pandemic. Some illustrative quotes, below, have been condensed due to space considerations.

Theme 1: Experiences of Caregivers During COVID-19

Changes in level of support

Caregivers described increased stress and burden resulting both from the loss of formal and informal

support systems which were shut down in response to the pandemic and from caregivers' COVID-19-specific fears related to having people in their homes and to traveling to appointments using public transportation. For example:

"Well, what I really need right now is respite." [chuckles] [...] "I need a break, and you know people in the group are saying, 'why don't you hire someone?'" [...] "I'm not letting anyone in here." [chuckles] "I don't know where they've been, who they've come in contact with. [...] But yet, I need help desperately."

"I wish there were eight days in the week. I don't have enough time to do everything that I have to do because I am the only one."

"All of our doctors are on 34th Street [...] and that's a big problem because, at this point, I am very uncomfortable taking any kind of mode of transportation – definitely not subways, which was a perfect mode of transportation for us. Buses – out of the question."

Caregivers also had fewer opportunities for in-person interactions that could provide social and emotional support.

"[Before the pandemic] He had his group, and I was able to [...] just stay there to relax. And I enjoyed talking to the other caregivers. I mean, I feel like I made connections with these, these people. And I miss them in many respects."

One caregiver noted his sense of loss on his partner's behalf and his concern about the impact of the lack of social stimulation on disease trajectory.

"I suspect being in isolation makes it difficult...more difficult for her because I think she responds to social stimulation, you know, she's more alert and alive. [...] So I think the isolation contributes [to negative outcomes]"

Changes in the relationship with the PWD

Caregivers were asked about changes in their relationship with the PWD during the pandemic. Three caregivers spoke about anger, frustration, and losing

patience with the PWD. Four mentioned negative relationship changes attributable to decline in the PWD's ability to function. Several caregivers described positive relationship changes due to being quarantined together and forced to find ways to connect since distancing from one another was not an option. They made comments such as:

"Of course, [COVID] affects our relationship and we go through periods of time when there's more anger, more on my part, struggle, obstinacy or stubbornness on her part or inability to respond. And we go through periods of time when we're warm and affectionate."

"We're really together, so I have to, and she has to, figure out ways of getting along."

"I'm much more aware of his fragility and then the fragility of our future and of the need to be very protective of him. [...] I think it just generally made me more caring and nurturing of him."

Caregiver stress due to differences in perception of the pandemic

Multiple caregivers reported that the PWD's inability to remember that they were in the midst of a pandemic, recall the dangers of COVID-19, and remember required protective measures contributed to their stress and frustration, as illustrated by the following quotes.

"I have to explain to him about the pandemic. I tell him it's worldwide and we are on a mandatory lockdown and if we go out, we must wear a mask, otherwise, we'll be fined. So, when we do get out, and I point out, I point out everyone who is wearing a mask. And sort of like to reinforce what I told him. But, of course, he doesn't remember from day to day"

"In some ways, I'm angry with him because he doesn't get it that we are living in a different environment."

Benefits and silver linings

Surprisingly, many caregivers described positive aspects of their pandemic experience including more frequent contact with others, as competing time

demands were reduced, and the barrier of physical distance was eliminated due to widespread adoption of videoconferencing. For example:

“And it was [...] the hour-long Zoom party, that had it not been for COVID, I would not have been invited to the party. It would’ve been for young people ‘cause they’re all around 40. This way, I got invited, and I got such satisfaction in seeing all these lovely young people from the past.”

“My daughter and granddaughters in Texas, for example. I now see them once a week, whereas I never, never would have before.”

Caregivers also expressed relief due to feeling less of an obligation to take the person with dementia on stimulating outings. For example, one caregiver noted the benefits of being freed from the pressure to engage in activities and coordinate and manage the complicated logistics required to get out of the home.

“Every time we went out for some activity [...], it was such a stressful, exhausting, physically exhausting, stressful experience. We don’t have to do it anymore and I’m almost really glad that we can’t go out.”

One caregiver found some comfort from the COVID-19 pandemic imposing an experience on everyone that he found akin to the “surreal” experience of caring for his wife with dementia.

“Overall, it hasn’t been negative. The way I see it is our life has been surreal since we’ve been dealing with dementia. And now, it feels like everybody’s life is surreal. So, it’s like everybody has joined us; this surreal world. So, in a way, there’s some comfort in that, which is kind of bizarre, but I do feel like everybody is kind of in our reality now.”

Theme 2: Caregiver Response to the FSP During COVID-19

General responses about the FSP

All caregivers described feeling supported by the FSP program, describing it in terms such as “indispensable,” “phenomenal” and “wonderful.” Caregivers noted that the online group offerings provided a place to talk with others who could understand

their situation and an outlet to express frustrations. The program also gave caregivers something to look forward to in their weekly schedules. Several caregivers also commented on the importance of the relationship with their social worker and other FSP services in helping them cope with pandemic-related issues. Comments include:

“It’s extremely helpful in terms of a place to ventilate, talk about problems, get very good feedback, get emotional support, get cognitive support, and feel that I belong to someplace where people understand what my situation is.”

“It was an outlet for all this fear, anger, anxiety that I have. I don’t know where else I could get rid of it.”

Online support groups

Some caregivers felt more supported and connected to program members with the transition to video telehealth, as exemplified by the following quotes:

“We connected [...] even more now that we’re doing Zoom than before... in a way that we started telling more of our personal stories. ... We know more about each other not just as caregivers but as people... So, I think in some bizarre way, this whole COVID experience has enriched our togetherness and our support for each other.”

“[during COVID-19] we shared the [phone] numbers realizing that it would be really helpful to all of us to know that we are there for each other not only on Thursday afternoon but other times also. I think that has been a very, very positive side.”

However, a few caregivers acknowledged initial awkwardness before they became comfortable with the video format. Other caregivers commented that video telehealth format diminished the connection they felt with group members. Some described changes in group dynamics related to difficulty hearing and seeing other group members:

“Not getting the physical aspect of the group – we would hug each other or there was a closeness that you can’t quite just duplicate online. But it’s working, so I’m happy about that.”

"I know this is inevitable with the Zoom technology but sometimes it's hard when our number is as much as 8 or 9 or 7 or 8...Very often, we're talking on top of each other, whereas in person, we defer to each other."

Suggestions for additional offerings by the FSP

Half of those interviewed had concrete recommendations for new program offerings. These recommendations included additional music programs and a more informal venue to connect with other caregivers.

Feedback about the need for opportunities to socialize was a catalyst for the creation of the new FSP "KaffeeKlatsch" (named after a Middle European pastime of meeting in a coffee house and chatting), which has been implemented with great success since March 2021. KaffeeKlatsch are offered by video twice a month and offer an informal venue for caregivers to socialize and share caregiving tips and experiences.

CONCLUSIONS

The current study aimed to understand the experience of dementia caregivers in their transition from in-person services to video telehealth services in order to hone and enhance future FSP programming. The findings are consistent with an emerging body of literature about dementia caregiving during the pandemic^{3,17,21,27} and support the value of the FSP online programming. Overall, caregivers were very satisfied with the FSP pre-pandemic and continued to feel supported by the FSP services provided via video. Caregivers transitioned to video telehealth services with little difficulty, which reduced concerns about the acceptability of delivering services via video telehealth. This finding is consistent with pre-pandemic studies that found high levels of satisfaction with telehealth,^{25,26,32,33} and with a recent study of a dyadic intervention demonstrating that dementia caregivers can utilize and derive equal benefit from telehealth interventions.³⁴ In fact, some of the FSP caregivers commented that video provided increased convenience and opportunity for connecting with others without the added burden of travel or need to find respite care for their partners.

However, several caregivers missed the opportunity for informal socialization that in-person support groups had organically provided. For example, the time before and after in-person groups was often used for socializing and some caregivers created opportunities for more socialization outside of group sessions.

Other downsides to video telehealth included the lack of opportunity for physical contact that diminished feelings of connection and reduced ability to gauge nonverbal feedback. While some of these concerns involve inherent limitations of video telehealth, the FSP has also taken steps to compensate for the new communication and group dynamic challenges posed by video telehealth. Older Adult Technology Services (OATS) works with NYU to provide FSP clients with information about best practices in using videoconferencing prior to enrolling in group events. In addition, some program staff have taken a more direct approach to moderating and facilitating participant interactions; for example, calling on specific individuals and redirecting conversations to ensure equitable participation.

While video telehealth services are frequently cited as beneficial for those in rural communities, socioeconomically disadvantaged groups, or homebound individuals, our findings suggest that such services are also advantageous for dementia caregivers, given the unique barriers cited by this population, including lack of time given caregiving responsibilities, lack of respite care for the PWD, and the additional burdens of travel time to access in-person services.³⁵⁻³⁷ Video telehealth should be thought of not just as a temporary stopgap measure during a pandemic, but also as a permanent option that can overcome barriers to care and social engagement. The current findings are consistent with research that has shown that social technology (e.g., Zoom and Facetime) can reduce loneliness and feelings of isolation among older adults.³⁸⁻⁴¹

Limitations of this study include the small sample size, although the research team determined that they had reached thematic saturation after 10 interviews. In addition, this study was limited to spouse or partner caregivers living with the PWD, so we cannot be sure the degree to which these findings apply to other informal caregivers such as adult children of PWD and caregivers not cohabiting with a PWD. Due to the demographic composition of the FSP group

members, our sample also consisted of predominantly white caregivers from high socioeconomic backgrounds, so it is unclear the degree to which these findings apply to other populations.

The pandemic caused a rapid shift in healthcare culture to the adoption of video telehealth. The FSP quickly adapted to the circumstances of the COVID-19 pandemic, transitioning to online services even before the official lockdown in NYC. Findings from our interviews have already been used by the FSP to improve and expand offerings and provide greater access to support via video telehealth. Overall, the qualitative interviews suggest that the efforts of the FSP to transition to online services were successful in meeting the needs of spouse and partner caregivers. Future quality improvement efforts will focus on broadening and evaluating services offered to adult child caregivers, those from underrepresented groups and those who live in socioeconomically disadvantaged neighborhoods.

AUTHOR CONTRIBUTIONS

Maureen K. O'Connor designed interview project and interviewed participants. Mary S. Mittelman designed the interview project and is responsible for oversight of the FSP offerings. Roscoe Nicholson led the qualitative analysis of interviews. Cynthia Epstein helped design the interview project and led participant recruitment. Rebecca Salant coded interviews. Tiffany Donley interviewed participants. Andrew H. Nguyen transcribed and coded

interviews. Steven Shirk helped design the interview project. Elizabeth Stevenson helped with participant recruitment.

DATA STATEMENT

This data has been previously presented at the Alzheimer's Association International Conference in July of 2021 in Denver, Colorado (USA).

DISCLOSURES

The authors report no conflicts with any product mentioned or concept discussed in this article.

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SUPPLEMENTARY MATERIALS

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