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Caregiver Experience of Tele-dementia Care for Older Veterans



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ABSTRACT

BACKGROUND: For the 5 million persons living with dementia (PLWD) in the USA, telemedicine may improve access to specialty care from their homes.

OBJECTIVE: To elicit informal caregiver perceptions of tele-dementia care provided during COVID-19.

DESIGN: Qualitative, observational study using grounded theory.

PARTICIPANTS: Informal caregivers aged 18+ who cared for an older adult who received tele-dementia services at two major VA healthcare systems participated in 30–60-min semi-structured telephone interviews.

INTERVENTIONS: Interviews were designed using Fortney's Access to Care model.

MAIN MEASURES: Thirty caregivers (mean age = 67, SD = 12, 87% women) were interviewed.

KEY RESULTS: Five major themes were (1) Tele-dementia care avoids routine disruption and pre-visit stress; (2) Transportation barriers to in-person visits include not only travel logistics but navigating the sequelae of dementia and comorbid medical conditions. These include cognitive, behavioral, physical, and emotional challenges such as balance issues, incontinence, and agitation in traffic; (3) Tele-dementia care saves time and money and improves access to specialists; (4) Tele-dementia facilitated communication between caregiver and provider without hindering communication between PLWD and provider; and (5) Caregivers described ideal future dementia care as a combination of virtual and in-person modalities with in-home help, financial and medical support, and dementia-sensitive caregiver access. Caregivers interviewed saved 2.6 h ± 1.5 h (range: 0.5 to 6 h) of travel time. Multiple caregivers described

disruption of routines as difficult in PLWD and appreciated the limited preparation and immediate return to routine post telemedicine visit as positives.

CONCLUSIONS: Caregivers found tele-dementia care convenient, comfortable, stress reducing, timesaving, and highly satisfactory. Caregivers would prefer a combination of in-person and telemedicine visits, with an opportunity to communicate with providers privately. This intervention prioritizes care for older Veterans with dementia who have high care needs and are at higher risk for hospitalization than their same age counterparts without dementia.

KEY WORDS: Dementia; Telemedicine; Informal caregiving

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BACKGROUND

During the COVID-19 pandemic, family caregivers experienced higher levels of stress and burden due to increased caregiving responsibilities, heightened vigilance, and social isolation.¹ These stressors were amplified by care recipients' behavioral and psychological symptoms of dementia, respite cancellations, and cancelled appointments. Hospitalized patients were discharged home sooner to keep hospitals open for COVID-19 patients, and post-acute care options were limited.² A recent survey of 576 family caregivers showed that caregivers reported higher anxiety, depression, fatigue, and sleep issues than non-caregivers. Caregivers who were women, younger, lower income, provided both personal and medical care, and cared for those with cognitive or behavioral problems reported worse outcomes.³

Some of these care recipients with cognitive and behavioral challenges are the estimated 5 million persons living with dementia (PLWD) in the USA. A survey of dementia

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caregivers in Italy early in the pandemic reported that 54.7% experienced worsening behaviors in care recipients including agitation, aggression, apathy, and depression.⁴ A study in Greece during the pandemic lockdown period reported increased behavioral and psychological symptoms in the PLWD and increased caregiver hyperarousal, avoidance symptoms, and COVID-19 worries.⁵ Some of the pandemic-related changes PLWD have experienced include difficulty complying with COVID-19 safeguarding procedures including masking, handwashing, and social distancing, further putting them at risk of contracting COVID-19.^{6–8} Compounding these challenges was the recognition that PLWD are at higher risk of hospitalization and death from complications of COVID-19.^{9,10,11}

PLWD and their caregivers particularly need specialty care access to address behavioral and psychological symptoms of dementia and caregiver stress. Telemedicine has the potential to improve this access and reduce related stresses. Telemedicine appointment uptake increased drastically during the pandemic. Specialty tele-dementia care and caregiver perspectives are of unique interest to general internists as they are often the first line providers addressing the behavioral and psychological symptoms experienced by those with dementia and are tasked with treating or referring to subspecialty expertise, when available.

OBJECTIVE

Despite the massive shift to telemedicine, little is known about how dementia caregivers experience telemedicine visits. The objective of this qualitative study is to examine the informal caregivers' perceptions, experiences, and satisfaction of specialty dementia care delivered through a telemedicine modality, hereafter termed "tele-dementia care," provided during COVID-19 pandemic. Tele-dementia care was intended to provide all the elements that would take place in-person: patient and caregiver interviews, diagnosis, pharmacologic and non-pharmacologic management, and was not viewed as a temporary measure until in-person care was available.

METHODS

Study Design

This study aimed at understanding the tele-dementia care program for older Veterans enrolled at two major Veteran Affairs (VA) medical centers in California and Ohio. This qualitative, observational study used grounded theory to answer the question, "What do caregivers report about their experience with receiving dementia care and specifically tele-dementia care?" The study was deemed exempt for human subjects' research by the relevant Institutional Review Boards (IRB#59643).

Participants

We recruited a convenience sample of 30 family caregivers of older Veterans who sought tele-dementia care between October 2020 and August 2021. The sample size of 30 was selected as data saturation is often reached within 9–17 interviews.¹² Since two sites were used, 15 interviews were conducted from each site. Eligible caregivers were English-speaking and > 18 years old, had telephone access, and could provide consent. Of 58 caregivers screened, 2 caregivers were excluded whose PLWD had died; 26 caregivers failed screening attempts as they did not answer the phone or felt too stressed to participate. Study staff contacted the caregivers, described the study, and obtained verbal informed consent. Some caregivers in this study used Veteran Affairs (VA)-provided tablets to receive tele-dementia care, while others used personal devices.

Survey and Interview

Caregivers participated in 30–60-min, telephone-based, semi-structured interviews between July 2021 and March 2022. The two interviewers (VN, MB) were trained qualitative researchers with experience interviewing informal caregivers in clinical settings. Audio recordings were transcribed for analysis.

The interview guide (Supplemental Appendix 1) was informed by Fortney's Access to Care model¹³ and included questions related to domains of access to care (geographical, temporal, and digital factors) as well as perceived access to care, utilization, satisfaction, and quality. The interview guide began with caregiver background questions, the home caregiving situation, caregiver's estimate of travel time to the main medical center, and PLWD's assistance needs. The guide elicited dementia care medical history and access to care and utilization and probed to elicit thorough, detailed descriptions of caregivers' experiences with Veterans' dementia specialty care. Caregivers were asked to describe the Veteran's experiences seeking care and treatment within and outside of the VA for dementia specialty care, as well as their experiences receiving care in-person versus via telemedicine. Caregivers were asked about time savings, ideal dementia care, and satisfaction with tele-dementia care on a 10-point scale. Caregivers were asked about post-pandemic care and the first 3 words that describe tele-dementia care. Caregivers were asked some optional, general demographic questions about their race, education, marital status, and financial situation. Financial situation was asked in the following manner: "Without telling us the exact amount, how would you describe your financial situation? I'm going to give you 5 options." Age, stage of dementia of the Veteran, and one way distance to VA medical center were abstracted from the medical record.

Results are presented below and include selected representative quotations. The section headings below the themes are subthemes.

Theme 1: Tele-dementia Care Avoids Routine Disruption and Pre-visit Stress

Limited Preparation for Visits and Immediate Return to Routine. Multiple caregivers described how they appreciated the limited preparation needed for a tele-dementia visit, including immediate return to routine post visit completion (Table 2, 1.1).

Pre-visit Stress Experienced by Caregivers and PLWD. In the absence of tele-dementia care, caregivers described needing many hours for visit preparation since the PLWD may not want to get ready and leave the home according to the planned schedule, or may have stress around changes in routine when they cannot control the activities of the day (Table 2, 1.2, 1.3, 1.4). A caregiver stated “it makes him decline actually... I wouldn’t even tell him up to the minute we were leaving because he would be so anxious” (Table 2, 1.5).

Even When Technical Issues Are Present, an Alternative to In-person Care Is Beneficial. Caregivers noted occasional technical issues that some participants faced (e.g., internet connection, speed of internet, grainy quality of the video). Despite this, participants interviewed still felt an alternative to in-person visits was beneficial (Table 2, 1.6).

Theme 2: Transportation Barriers to In-person Visits Include Not Only Travel Logistics, But Navigating the Sequelae of PLWD’s Dementia and Other Comorbid Medical Conditions

Caregivers described that transportation included exiting the house, entering the car safely, driving to the facility, parking, exiting the car, and walking to the building and into the clinic.

Cognitive Barriers to Transportation: Attention and Executive Function Challenges. Many caregivers described their PLWD as having an inability to follow instructions. Caregivers described opening their front door and having the person with dementia elope or refuse to get in the car. They also described behaviors such as locking and unlocking doors (Table 2, 2.1).

Perceptual Disturbances—Hallucinations. Multiple caregivers described auditory and visual hallucinations and delusions present in the PLWD that made staying home and leaving difficult (Table 2, 2.2).

Physical Challenges. Multiple caregivers noted that their PLWD encountered numerous physical challenges including loss of balance, incontinence, hearing and vision loss that made exiting the house and entering the car difficult when trying to access in-person care (Table 2, 2.3).

Emotional, Cognitive, and Physical Challenges Together. One caregiver stated her husband had “... nervousness issues, where he ends up having bowel movements” (Table 2, 2.4). Additionally, several caregivers described their PLWD’s fear and stress in traffic created potentially dangerous driving situations. When in the car, many caregivers experienced stress as some PLWD demonstrated unsafe passenger behaviors that were distracting “he would get so scared in the traffic, I don’t know how I could drive and keep him calm” (Table 2, 2.5). Another confessed she felt “I’m going to have a wreck, just because you’re scaring me!” (Table 2, 2.6). One caregiver takes a bus after PLWD had license suspended so “I don’t have to deal with his arguing and trying to tell me what to do.” (Table 2, 2.7).

Navigating Parking and Walking from Car to Clinic with PLWD Is Challenging. When caregivers arrived at the medical center, they could not leave their PLWD unattended, but also struggled physically with getting them from the parking spot to the facility. One caregiver described “Drop him off, get him in, get him sat down, and then I go back to the car, go across the street with my vehicle, park in the parking lot, come flying back across as fast as I can” (Table 2, 2.8).

Theme 3: Tele-dementia Care Saves Time and Money and Improves Access to Specialists

When asked how much time saved, answers varied widely. Caregivers reported they saved $2.6 \text{ h} \pm 1.5 \text{ h}$ (range: 0.5 to 6 h) of travel time.

Avoiding Travel Saves Money. Caregivers reported that avoiding travel-related costs like gas saves money, and the hassle of filing for travel reimbursement (Table 2, 3.1).

Accessing Dementia Specialty Care Is Hard and Older Adults Can Benefit from Specialized Medical Professionals. One caregiver described difficulty finding Lewy body dementia specialists in her geographical area, “We have nobody in our area... We don’t even have a nursing home or memory care.” (Table 2, 3.2). Another caregiver appreciated the geriatrics specialty care for dementia “Senior citizens have special needs and things that are happening to them just because of their age, and they need a doctor that specializes in that area.” (Table 2, 3.3).

Table 2 Representative Quotes

Theme 1. <i>Tele-dementia care avoids routine disruption and pre-visit stress.</i>	
Subtheme	Limited preparation for visits and immediate return to routine
1.1	"I was very grateful, because it would have been like a half a day. So, it saved me several hours, because you get up, get prepared. We really didn't have to do anything; we followed our normal routine and just stay here at home. So, it's very comfortable, like I said it saved me hours. And then we didn't have to drive back or whatever, so we were comfortable being able to sit in our home. And after it was over, I was able to give him a snack and carry on with our routine. So that was the great part about it." (70-year-old, Black female, spouse caregiver of a Veteran with moderate-severe dementia)
Subtheme	Pre-visit stress experienced by caregivers and PLWD
1.2	One spouse caregiver said, "I'd have to wake him up at 3:00 in the morning just to give him time to get him ready, get him fed, get him out the door. He was so anxious and it made it very difficult. It just made a horrible day. He would actually be like, 'Why didn't you tell me? Why'd you forsake me? Why didn't you tell me I had an appointment?' Things like that. It was just horrible." (55-year-old, White female, spouse caregiver of a Veteran with moderate dementia)
1.3	"And sometimes when he's as stubborn as a mule, just won't cooperate at all, won't even wake up; and then other time he's just anxious to help please and do as much as he can possibly do." (80-year old, White male, brother-in-law caregiver of a Veteran with Moderate-Severe Dementia)
1.4	"Well, I will try to get him up at 7:00, which is plenty of time for him to get dressed, even if he takes his shower if he's willing to take a shower. For him to get dressed once he gets up, it only takes him an hour. But usually, the actuality of it all is it's an hour and a half, two hours. And sometimes we miss our appointment because I can't get him moving if he fights me. And then he's slow. He wanders. He drifts off. And I try to get on top of him and remind him verbally in a pleasant tone and he gets upset. He just gets upset with me." (76-year-old, White female, spouse caregiver of a Veteran with moderate-severe dementia)
1.5	"it makes him decline actually... I wouldn't even tell him up to the minute we were leaving because he would be so anxious. He would think he would have to remember that whole time. They really do try to do things for themselves. They really do try." (55-year-old, white female, spouse caregiver of a Veteran with moderate dementia)
Subtheme	Even when technical issues are present, an alternative to in-person care is beneficial
1.6	I had a little bit of difficulty, because like I said I'm not really that computer savvy. We have no internet, we do everything through the cellular phone. So that's about the extent of my ability. As far as virtual stuff, it seems like it's a genuine try at doing something for you, and the video thing adds a little dimension, where they can see how you're acting or what you're doing or if there's an injury, what's going on. Versus taking a chance at catching something worse going into the doctor's office. (60-year-old, White male, son caregiver of Veteran with Mod-severe Dementia)
Theme 2. <i>Transportation barriers to in-person visits include not only travel logistics, but navigating the sequelae of PLWD's dementia and other comorbid medical conditions</i>	
Subtheme	Cognitive barriers to transportation: Attention and Executive Function Challenges
2.1	"...he walks out the door, locks the door. He's very mobile, he's goes and goes, he's manic, actually. Like he does not stop. He does not stop and sit down." (32-year-old, White female, granddaughter caregiver of Veteran with mild dementia)
Subtheme:	Cognitive barriers to transportation: Perceptual disturbances—Hallucinations
2.2	"there's been times that he says he hears—he has hallucinations a lot, and he's opened up doors and set off our alarm, so we know he's opening doors when the alarm goes off. And he goes, "Well, somebody was outside." And I was like, "Nobody's outside." He'll go, "Well, they were calling my name." (59-year-old, White female, daughter caregiver of Veteran with mild dementia)
Subtheme	Physical challenges
2.3	"...he has trouble seeing, so I'll let him know if something's coming up, a step or you know, something he needs to be aware of. Sometimes I help him get in the car, because he has trouble getting one leg in." (61-year-old, white female, spouse caregiver of Veteran with mild dementia)
Subtheme	Emotional, cognitive, and physical challenges together
2.4	"...nervousness issues, where he ends up having bowel movements, he doesn't make it to the bathroom. So that worries me. That worries me, is that I can't go in the men's bathroom there and help him clean himself up or anything like that. So that's one of the big things about going in-person that bothers me, is him having accidents." (71-year-old, Hispanic female, spouse caregiver of Veteran with mild dementia)
2.5	"...he would get so scared in the traffic, I don't know how I could drive and keep him calm...he either gets very angry and agitated or he gets violent." (70-year-old, White female, spouse caregiver of a Veteran with severe dementia)
2.6	"...then you've got to get in the car, then you've got to drive home. Then you've got to park the car, get out of the car. And sometimes it's smooth and sometimes it's not. Then I'm driving and my husband is saying, 'Watch it, hold it!' I'm going to have a wreck, just because you're scaring me!" (70-year-old, black female, spouse caregiver of a Veteran with moderate-severe dementia)
2.7	"His license has been suspended because of the dementia and Alzheimer's. So it makes it easier if we just ride in the bus. That way I don't have to deal with his arguing and trying to tell me what to do." (76-year-old, White female, spouse caregiver of a Veteran with moderate-severe dementia)
Subtheme	Navigating parking and walking from car to clinic with PLWD is challenging
2.8	"Drop him off, get him in, get him sat down, and then I go back to the car, go across the street with my vehicle, park in the parking lot, come flying back across as fast as I can, and then I get him into transport at the VA, and transport and stuff like that." (75-year-old, White female, spouse caregiver of a Veteran with moderate dementia)
Theme 3. <i>Tele-dementia care saves time and money and improves access to specialists</i>	
Subtheme	Avoiding travel saves money
3.1	"Yeah, and it saves money when you have a limited income, it saves money, it helps a lot with the gas and stuff like that. I always forget to file for it [travel reimbursement] sometimes now, it was easy before. But anyway, I don't go that much so I don't file for it." (72-year-old, White female, spouse caregiver of a Veteran with severe dementia)
Subtheme	Accessing dementia specialty care is hard and older adults can benefit from specialized medical professionals
3.2	"We have nobody in our area. Like I said, even our neurologist's office in our area closest to us, and it's another county away, they just closed. I don't know of anybody in our whole area that would specialize in any dementia, let alone Lewy body. We don't even have a nursing home or memory care. We have one place in...county that has six beds, and they don't specialize in Lewy body." (55-year-old, White female, spouse caregiver of a Veteran with moderate dementia)

Table 2 (continued)

3.3	“I would recommend the geriatrics for—actually, for their whole care. There should be physicians that specialize in older patients. Like, when I used to work in the children’s hospital, the doctor I was working for said, ‘You know, children are not just small adults. You need a doctor that specializes in children,’ and I think it’s the same with senior citizens. Senior citizens have special needs and things that are happening to them just because of their age, and they need a doctor that specializes in that area.” (79-year-old, White female, spouse caregiver of a Veteran with mild dementia)
Subtheme	Avoiding COVID exposure
3.4	“...he doesn’t understand, and so it’s like if you try to tell him, ‘No, don’t do this’ or whatever, it’s like, ‘Well, I want to do it, so I’m going to do it anyway.’ He doesn’t understand the COVID procedures...he’s had his shot and he wears a mask, so his main problem is the hands and getting too close to others. Yeah, he’s a very touchy-feely kind of person, you know, touch your shoulder, touch your hands.” (59-year-old, White female, daughter caregiver of a Veteran with mild dementia)
Theme 4.	<i>Tele-dementia facilitated communication between caregiver and provider without hindering communication between PLWD and provider</i>
4.1	“I generally like to do it in person. That’s usually what I prefer. But the one advantage to doing it on video is that if I can get him to leave the room, then I can actually talk without the interruptions. Where if we’re coming to [City] and in the office with Dr. [NAME] there’s nowhere I can go because he keeps track of me. He doesn’t want me saying anything and so if I were to leave the room, he would follow me. Or if I were to have him go out of the room first and then lag behind, he would come back and take me by the hand out of the room.” (76-year-old, White female, spouse caregiver of a Veteran with moderate-severe dementia)
Subtheme	“Truth” telling is different for the PLWD and the caregiver
4.2	“Because when I go into an appointment with him, he shuts me down and he argues with everything I say and so it’s so helpful for me to be able to talk with the doctors in private ahead of time to let them know that—I want him to share his feelings too, but so much of what he says is not correct. It’s not real, especially the issue about his drinking. And now, thank goodness, the past month he hasn’t been drinking that much so that really has helped a lot with his cognitive.” (76-year-old, White female, spouse caregiver of a Veteran with moderate-severe dementia)
4.3	“It’s mainly not being able to communicate with the professionals, with the doctors and things, easily, without him interrupting all the time. So, that’s one of my main frustrations.” (76-year-old, White female, spouse caregiver of a Veteran with moderate-severe dementia)
Subtheme	In-person communication is challenging for PLWD when providers are masking
4.4	“If I concentrate, I can gather what he’s saying, but my husband cannot. He tunes it out because he can’t understand. And especially when you had to wear the masks. It’s difficult to understand anybody with a mask on.” (76-year-old, White female, spouse caregiver of a Veteran with moderate dementia)
Theme 5.	<i>Caregivers described ideal future dementia care as a combination of virtual and in-person modalities with in-home help, financial and medical support, and dementia-sensitive caregiver access</i>
Subtheme	Caregivers hope to use tele-dementia services beyond the pandemic
5.1	“...nothing takes the place of in-person visits. So, I would want to still do that at least once a year, for his different specialty people. But in between, maybe have checkups online. But I would not want to only do online, and probably not always have to go into the clinics. So, I’d take a mixture.” (75-year-old, White female, spouse caregiver of a Veteran with mild dementia)
Subtheme	Caregivers feel calmer and with less stress during tele-dementia visits
5.2	“I kind of tend to think that I’m more calm virtually. I guess I tend to think that because it’s a whole stress thing, getting ready to get out, you know, getting things settled, get the animals settled and everything, get [Name of Veteran] done and get myself done, and get out. It’s a whole stress thing, every time we go out for any appointment or anything, it’s a stress thing. So you get in the car, you take a big deep breath and woo, okay, now we’re on our way.” (71-year-old, Hispanic female, spouse caregiver of a Veteran with mild dementia)
Subtheme	Caregivers described what an ideal future state of dementia care would be like, both for their PLWD and for caregivers
5.3	“In the ideal world? More caring. More caring and understanding, and more of an effort for people to realize that a lot of people are afraid of it and they think it’s contagious. When somebody gets dementia, you don’t see any friends or family anymore. It’s lonely. It’s very lonely, so I would say if you could see that change.” (55-year-old, White female, spouse caregiver of a Veteran with moderate dementia)
5.4	“Oh, I have, I have dreamed. I would love for him to have someone come in, at least every other day, like Monday, Wednesday, Friday and Saturday or one of the days on the weekend. Just another day, because that would just be wonderful. I wish that our bathroom was converted to wheelchair accessible, so that he could just walk into the shower and I could let him take a shower.” (70-year-old, Black female, spouse caregiver of a Veteran with moderate-severe dementia)
5.5	“I wish there was a handyman type of home health aide, that wouldn’t mind being outside with him, like raking leaves or shoveling snow if it’s winter. But just things that he can feel like he’s accomplishing some things and not just sitting here watching television, that kind of thing, that wouldn’t mind just sitting outside and counting cars and looking at motorcycles.” (70-year-old, Black female, spouse caregiver of a Veteran with moderate-severe dementia)
5.6	“I just wish that there was funding or help that could be provided. And not just a lot, but just little things, like you said, maybe to encourage us, the caregiver and the family. I know that I can apply for grants and I think we’re not on the economic poverty level, so we don’t qualify like that. There ought to be something for moderate income families, to be able to get some of the things that would just provide a little more comfort, especially because we are at home and we are trying to do things. I know everybody needs money and everything, but it would just be nice if some type of grant or something would be available to people, just the average American family, who just needs a little extra, to be encouraged to continue this. Because a lot of us don’t want to put our loved one in a home and don’t want to have to give up everything to do that.” (70-year-old, Black female, spouse caregiver of a Veteran with moderate-severe dementia)

Avoiding COVID Exposure. A few caregivers appreciated the avoidance of COVID-19 exposure “He doesn’t understand the COVID procedures...he’s had his shot and he wears a mask, so his main problem is the hands and getting too close to others.” (Table 2, 3.4).

Theme 4: Tele-dementia Facilitated Communication Between Caregiver and Provider Without Hindering Communication Between PLWD and Provider

Even Though Caregivers Like In-person Visits, It Is Easier for Both PLWD and Caregivers to be Heard During Tele-dementia Visits. One caregiver described “the one advantage to doing it on video is that if I can get him to leave the room, then I can actually talk without the interruptions...” (Table 2, 4.1).

“Truth” Telling Is Different for the PLWD and the Caregiver. “Truth” telling seemed to refer to the accuracy of information given by the PLWD to the care provider. For example, the PLWD may mis-remember and report inaccurate information about current state (Table 2, 4.2). Another caregiver expressed appreciation to talk to the provider before or after scheduled visits (Table 2, 4.3).

In-person Communication Is Challenging for PLWD When Providers Are Masking. In the COVID-19 era, masks and face-shields are necessary safeguarding for healthcare professionals, but this too can be problematic for some patients, especially those with sensory impairments like hearing. Although tele-dementia can also be challenging for those with hearing impairment, at times providers may be able to speak over video or telephone without a mask on “It’s difficult to understand anybody with a mask on.” (Table 2, 4.4).

Theme 5: Caregivers Described Ideal Future Dementia Care as a Combination of Virtual and In-Person Modalities with In-home Help, Financial and Medical Support, and Dementia-Sensitive Caregiver Access

Caregivers Hope to Use Tele-dementia Services Beyond the Pandemic. Caregivers hope to continue using tele-dementia services beyond the pandemic due to the convenience, especially as the disease advances and getting out of the home becomes increasingly difficult. However, they did not want to eliminate in-person visits completely “I’d take a mixture.” (Table 2, 5.1).

Caregivers Feel Calmer and with Less Stress During Tele-dementia Visits. One caregiver reflected upon the way she shows up to tele-dementia visits versus in-person

visits. “I kind of tend to think that I’m more calm virtually.” (Table 2, 5.2).

Caregivers Described What an Ideal Future State of Dementia Care Would Be Like, Both for Their PLWD and for Caregivers. Caregivers discussed how they had dreamt about this and provided comments about an ideal future state. “In the ideal world? More caring.” (Table 2, 5.3). They also described respite care coming “at least every other day” (Table 2, 5.4) and wishing there was a “handyman type of home health aide, that wouldn’t mind being outside with him, like raking leaves or shoveling snow” (Table 2, 5.5). They also described hope for financial assistance for “middle class” caregivers “Because a lot of us don’t want to put our loved one in a home and don’t want to have to give up everything to do that.” (Table 2, 5.6).

Words Describing Caregivers’ Tele-dementia Experiences

Satisfaction with the tele-dementia services at the VA was expressed ($m = 8.6$; $SD = 1.9$) on the 1 to 10 scale. A word cloud was generated from caregiver responses regarding how they would describe their experience. The more frequently a word was used by the caregivers interviewed, the larger the word’s size was in the corresponding graphic (Fig. 1).

Our findings are illustrated in Fig. 2.

DISCUSSION

The key findings of this study are that tele-dementia care has the potential to alleviate not only the logistical and transportation challenges experienced by caregivers when trying to receive in-person dementia care, but also behavioral and COVID-19-related challenges. PLWD were able to receive specialty dementia care in their homes through this program and the dyad of caregiver and PLWD were able to communicate effectively with providers. Caregivers found tele-dementia care to be convenient, effective, stress reducing, safe, satisfactory, time saving, and highly valued.

Prior tele-dementia studies largely characterize barriers and facilitators to engaging in tele-health,¹⁹ or focus on the physician experience.²⁰ Care models involving telehealth and dementia care differed in that they utilized care navigators and nurses to provide support²¹ or used asynchronous telehealth for non-pharmacologic support for dementia behaviors.²² Transportation studies have mainly reported on the loss of driving in those diagnosed with dementia²³ or use of transportation assistance.²⁴ As one of the first studies to explore the challenging layers that dementia caregivers face when trying to obtain specialty dementia care, we add to the research by describing the processes that compromise transporting a PLWD from the home to the clinic.

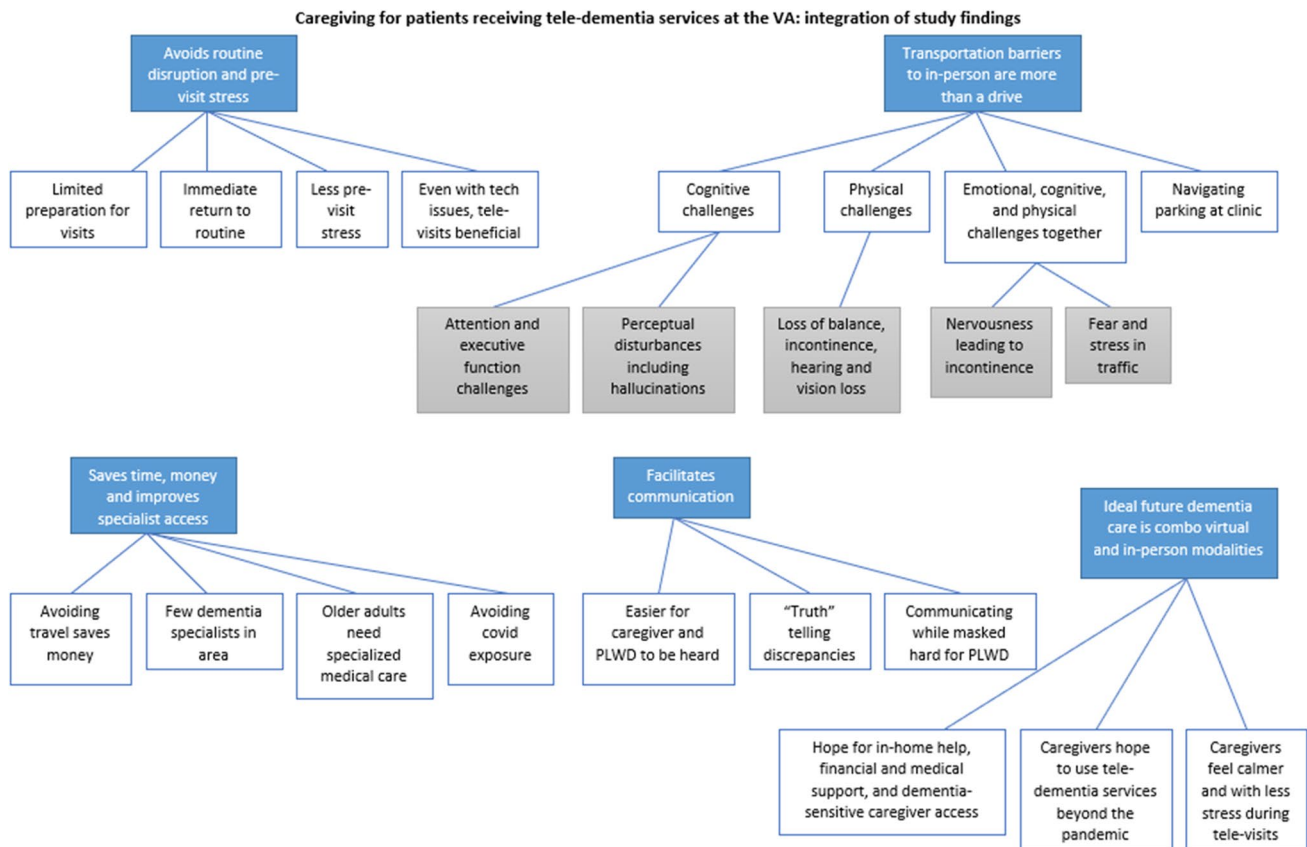


Figure 2 Summary of themes and subthemes.

Caregivers detailed the sequential pre-visit tasks that need to be completed by the PLWD to be transported. Despite vehicle availability, a confluence of other factors must align. The PLWD must follow directions, and not have any behavioral issues that preclude safely entering or sitting in a car. The appropriate time, patience, physical assistance, and cueing may be needed to get the PLWD ready for the appointment. In cases where these factors do not align, such as if distress behaviors preclude safely entering the vehicle, the PLWD would be unable to safely get to in-person appointments on time. When dealing with PLWD, services providing transportation assistance are necessary, but not sufficient to meet the needs of this population. Additionally, the cost savings of tele-dementia care noted by caregivers also predates a period of high gas prices, so the monetary relief could be even more pronounced in periods of higher gas price fluctuations. From the caregiver perspective, tele-dementia care overcame all these transportation and logistics-related challenges because the visit was integrated into the daily routine with minimal disruption. Tele-dementia care avoids amplifying behavioral challenges that are often present from changing environmental triggers. Some of these avoidance advantages are due to the virtual modality in general, but others are specific to tele-dementia care.

Communication was a second notable area from our study. The caregiver's remarks about PLWD having difficulty understanding providers with masks raise an important consideration

about whether in-person communication with masks and face shields is clearer than tele-health communication. Additionally, the ability for both the dyad of dementia caregiver and PLWD to be heard by medical providers during visits is very important for future dementia healthcare design. The discrepancies we uncovered in "truth" telling between the caregivers and PLWD are common and may be attributed to "anosognosia," or an impaired awareness of the deficits associated with dementia.²⁵ Additionally, when behavioral and psychological symptoms of dementia are present, the caregiver would benefit from direct discussion with the provider on management strategies.

The implications of asking caregivers to describe both their own experiences and Veterans' experiences with seeking dementia care and treatment are to understand the real problems Veterans face. Family caregivers, who experience daily life alongside individuals with dementia, provide valuable insight into the lived experience of those with dementia and family caregivers. We recognize this is a limitation; however, informant reporting is used frequently in dementia care.

This study has several limitations that may influence the interpretation and transferability of results. Our sample was based on a convenience sample of caregivers identified by physicians which may have led to selection and inclusion bias. Also, our sample was largely homogenous in gender, race, spousal relationship, and cohabitant status and only included caregivers of Veterans with medical care at the

Veterans Health Administration (VHA), which may affect the variability of experiences that were captured. The experience of Veterans may not be generalizable outside of the VA given that all participants had access to services, medications, and supplies provided by the VHA. This was a pilot program evaluation and was conducted while also rapidly disseminating this clinical care in the context of notable healthcare changes during COVID-19 pandemic including clinic closures and emergency protocols, so providers could not specifically train in tele-dementia care. It remains to be seen if the program remains equally acceptable when in-person care becomes more available. Despite these limitations, the caregivers' level of acceptability of tele-dementia care even with technical difficulties suggests that this is a way to deliver high-quality care ongoing as the pandemic waxes and wanes.

Strengths of this study include the design, attainment of rich qualitative data, timeliness and relevance of the results. Although spousal caregivers are the majority of caregivers represented here, 30% of caregivers are other relatives. Caregiver demographics of primarily women are consistent with national statistics that two thirds of dementia caregivers are women nationally.²⁶

Systems level challenges do exist that make enacting tele-dementia care difficult. Policy supporting telemedicine is currently largely under emergency use authorization from the COVID-19 pandemic and varies by state. We recommend that policymakers continue considering the role of tele-medicine in caring for older adults and support tele-dementia care as a reimbursable care model beyond the pandemic. By continuing to utilize telemedicine, access to hard-to-reach specialty care can improve. Caregivers are often left out as members of the care-recipient's health care team²⁷ and standards for incorporating caregivers into outpatient settings are nonexistent. Visitation restrictions applied institutionally during the pandemic negatively affected caregivers and PLWD.^{28,29} As we recognize the difficulty for health systems to engage caregivers, we point out the value in developing business cases for consistently incorporating caregivers into care and capturing this benefit.²⁷ Additionally, we recommend that if dementia caregivers need to cancel in-person appointments due to a variety of factors, attempting tele-dementia care, instead of rescheduling appointments, can be beneficial to all parties. Recognizing and addressing the unique challenges of transporting PLWD must be a priority for healthcare systems. At a family level, having appointment offerings that miss high traffic hours could also be helpful for those with dementia as multiple caregivers described how sitting in traffic negatively impacts a PLWD's mood and behaviors, to the point of putting them in dangerous driving situations. Additional transportation assistance from parking lots to clinics would help many caregivers and care recipients.

CONCLUSIONS

Caregivers found tele-dementia care to be convenient, effective, stress reducing, safe, satisfactory, and time saving, and see this care modality as a part of ideal future state dementia care. Tele-dementia services prioritize care for older Veterans with dementia who have high care needs and are at higher risk for hospitalization. This care complements in-home support services to help older adults with dementia age in place. It can also leverage access to specialty care and can be scalable beyond a healthcare system level to a regional or national level. Tele-dementia care is also consistent with and contributes to "age-friendly" care.³⁰ Future directions may include measuring program effectiveness and ability to prevent emergency room visits or delay institutional care, and looking into differences in caregiver responses based on education and occupation. However, this need for additional evaluation is balanced with the real-world need to care for an increasing number of older adults with dementia, complex psychosocial needs and multiple medical conditions, and a declining geriatrics subspecialist workforce.^{31,32} Our study illustrates that caregivers welcome tele-dementia specialty care, not simply as a temporary measure to mitigate the risk of the pandemic, but also as a permanent feature of specialty dementia care to mitigate safety and stress of managing PLWD.

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Declarations

Conflict of Interest The authors declare that they do not have a conflict of interest.

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