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Responding to the Needs of Persons Living With Dementia and Their Caregivers During the COVID-19 Pandemic: Lessons From the Care Ecosystem

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Abstract

Background and Objectives: The coronavirus disease 2019 (COVID-19) pandemic created challenges for persons with dementia, their caregivers, and programs that support them. The Care Ecosystem (CE) is a model of dementia care designed to support people with dementia and their family caregiver dyads through ongoing contact with a care team navigator (CTN) and an expert clinical team. CTNs provide support, education, and resources and help dyads manage dementia-related concerns as they evolve over the course of the disease. We aimed to understand how the CE responded to the needs of dyads during the initial 3 months of the COVID-19 pandemic.

Research Design and Methods: We conducted a survey and qualitative interviews with staff members from 4 established CE programs located in 4 different states to explore (a) challenges dyads voiced during the pandemic, (b) CE staff approaches to addressing the needs of dyads, and (c) programmatic challenges faced and lessons learned.

Findings: Nine staff members from 4 CE programs with an active collective caseload of 379 dyads were interviewed. Themes were identified that included dyad concerns regarding fear of illness, changing attitudes toward long-term care, decreased availability of services and resources, and impacts on patient and caregiver health and well-being. Programmatic challenges included maintaining effective communication with dyads and program staff, technological readiness, workflow restructuring, and program sustainability.

Discussion and Implications: Approaches in supporting people with dementia and their caregivers should demonstrate flexibility, responsivity, and creativity, and these findings provide insight for understanding how dementia care programs can be positioned to offer continuous support for this vulnerable population.

Translational Significance: During the pandemic, persons with dementia and their caregivers reported concerns relating to viral exposure, functional and behavioral decline of the person with dementia, difficulty accessing resources, changing attitudes toward long-term care, and experiences of loneliness and isolation. The Care Ecosystem, a supportive dementia care model, faced challenges relating to program sustainability and workflow. Telephone-based and scheduled contacts with dyads, along with strong organizational and community partnerships, were factors in supporting dyads. Results from this study inform programs on ways to support persons with dementia and their caregivers during unexpected events that threaten public health and safety.

Meeting the needs of persons with dementia and their caregivers is challenging and complex. As the person with dementia experiences decline in cognitive, behavioral, and functional abilities, their caregivers must adapt and assume greater responsibility for care involving medical and financial decision making, daily activities, quality of life, and safety. Amidst these already difficult aspects of caregiving, the coronavirus disease 2019 (COVID-19) pandemic created unique challenges for persons with dementia and their caregivers (referred to as "dyads") that included increased vulnerability to illness and death (Liu et al., 2021). Almost 80% of deaths due to COVID-19 occur among people older than the age of 65 with multiple chronic conditions (Brown et al., 2020; Centers for Disease Control, n.d.). Among a cohort of 12,863 community-dwelling older adults in the United Kingdom, dementia was an age-independent predictor of COVID-19 infection, COVID-19-related hospitalization, and COVID-19-related mortality (Tahira et al., 2021; Wang et al., 2021). A 16% higher-than-expected mortality rate due to Alzheimer's disease in 2020 also reflects the broader impact the pandemic has had on this vulnerable population (Alzheimer's Association, 2021). As a result of the pandemic, family members caring for a person with dementia experienced higher rates of depression, anxiety, burden, and loneliness (Altieri & Santangelo, 2021; Anderson et al., 2021). Their increased distress has been linked with managing cognitive and behavioral symptoms of the person with dementia alongside worries due to COVID-19 (Alexopoulos et al., 2021). In addition, family caregivers have described their experience during the pandemic as one of loss, despair, stress, and exhaustion (Bacsu, 2021).

Programs and services that support these dyads were disrupted due to the pandemic, and that disruption is linked with these negative outcomes. For example, physical distancing and other public health restrictions caused major breaks in community services, such as day programs. The decreased access to community support services contributed to social isolation and loneliness (Giebel et al., 2021; Kotwal et al., 2021) as well as behavioral exacerbations and more rapid cognitive and functional decline (Canevelli et al., 2020; Simonetti et al., 2020). It has been noted that the increased demand on health systems for acute and intensive care diverted resources from patients with chronic diseases such as dementia (Brown et al., 2020).

Prior to the pandemic and given the numbers of people with dementia in this country, there has been great attention to designing strategies that support positive outcomes for this population and their caregivers. The Care Ecosystem (CE) is a model of dementia care designed to support these dyads. Unlicensed care team navigators (CTNs) are trained and guided by care protocols to screen for dementia-related needs and provide personalized support, information, and resources. CTNs are supervised by licensed clinicians with dementia expertise in nursing, social work, and medicine/pharmacy. This clinical team assists with complex situations and needs that go beyond the scope of the CTN role, for example, responding to new, distressing, and unsafe behavior symptoms that may require medical evaluation and treatment. CTNs are the primary point of contact for dyads and they primarily communicate by telephone and electronic messaging. The Care Ecosystem programs that participated in this study are embedded in health systems that serve the aging population, with a specific focus on those with cognitive impairment and dementia. Providers (physicians, neuropsychologists, nurses, and social workers) refer patients to the program.

A social support framework serves as a structure in organizing how the Care Ecosystem staff responds to dyad needs (Williams et al., 2004). In a prior study of our program, three categories of social support guided care planning that included informational (i.e., education and information), emotional (i.e., active listening and responding to emotional distress), and instrumental (i.e., connecting to resources and providing service; Merrilees et al., 2018). In a pragmatic randomized trial, the Care Ecosystem reduced caregiver depression and burden and improved quality of life and reduced emergency room visits for people with dementia after 1 year (Possin et al., 2019).

In March 2020, when public health campaigns to stop the spread of COVID-19 first mobilized across the United States, four health systems in four different states (California, Colorado, Louisiana, and Minnesota) had well-established Care Ecosystem programs to enhance dementia care in

their respective clinic settings. In this study, we aimed to understand how these programs responded to the changing needs and challenges of their staff and their participants during the initial 3 months of the COVID-19 pandemic. Findings from this study will help characterize the experience of dyads during the early stage of the COVID-19 pandemic, as well as program-level lessons learned from the Care Ecosystem teams responding to the unprecedented challenges and uncertainties during this period.

Method

Approach

In this qualitative study, we leveraged four Care Ecosystem programs located around the country. We sought to understand the needs of people with dementia and their family caregivers during the time that shelter-in-place restrictions took place from March to May 2020. In addition, we sought to understand how the programs responded to pandemic-related challenges and maintained care delivery while adjusting to working from home. Of note, we use the term "pandemic" to refer to the risk of viral exposure, illness caused by the virus, the mandates and policies addressing mask-wearing and physical distancing including shelter-in-place orders, and the impact that it had on people's livelihood and abilities to manage dementia and caregiving-related concerns.

Settings and Participants

Nine staff members from four established Care Ecosystem programs located in four different states participated. The four sites included an academic health system in Denver, Colorado, an integrated health system in St. Paul, Minnesota, an academic integrated health system in New Orleans, Louisiana, and an academic medical center in San Francisco, California. During this study period, the four programs were collectively caring for 379 active dyads. The participants interviewed included clinical staff (CTNs, nurses, social workers, physicians) and administrative staff (project directors or managers). Two participants served both clinical and administrative roles at their sites, and all sites had representation in this study from both clinicians and administrators.

Data Collection

We focused on the specific shelter-in-place time periods for each state (Minnesota: March 27–May 14, 2020; Louisiana: March 23–May 14, 2020; California: March 19–May 12, 2020; Colorado: March 26–May 8, 2020). Multiple authors from our multidisciplinary team (J. Merrilees, J. Robinson-Teran, A. Bernstein Sideman, S. Dulaney, M. Allawala, and K. L. Possin) helped to develop and refine the interview guide. Interviews were conducted by J. Merrilees and J. Robinson-Teran (authors). Staff were asked if they would be willing to engage in open-ended interviews for this project. They provided verbal consent (IRB #20-29974) to participate, and their interviews were conducted on Zoom, audio-recorded, and transcribed. Interviews lasted 50–60 min. All interviews covered the following topics: (a) the types of needs and challenges reported by dyads during the study period, (b) approaches staff used to address the needs identified, and (c) facilitators and barriers that affected CE staff efforts to address their dyads' needs. Project managers were also asked about the impact of the pandemic on Care Ecosystem program implementation, specifically around staffing and program sustainability. Study participants completed an anonymous electronic survey using Qualtrics that included multiple-choice and open-ended questions used to collect demographic data and information about working from home, use of technology, and strategies for maintaining confidentiality with Personal Health Information (PHI). We conducted nine open-ended qualitative interviews. Six of the participants completed the online surveys.

Analysis

We used thematic analysis to analyze the data. Two authors (J. Merrilees and J. Robinson-Teran) reviewed all of the raw interview transcripts independently and inductively coded all of the data (Thomas, 2006). They met regularly (weekly for several months) while conducting this inductive coding to discuss codes that were emerging and develop code definitions. When they had disagreements in coding, they returned to the raw material to analyze exemplary quotations and come to an agreement about the code used. They developed a preliminary codebook based on this inductive coding. This codebook, which included codes, code definitions, and exemplary quotations, was reviewed by a multidisciplinary team consisting of a medical anthropologist (A. Bernstein Sideman), advanced practice nurse (J. Merrilees), and research coordinator (J. Robinson-Teran). Throughout the process, when a team member felt there needed to be an adjustment to a code, the rest of the team reviewed the code, code definition, and example quotations. They worked together to either revise the code after returning to the data or come to an agreement to keep the code that was initially used after further review and discussion. Using the final codebook, J. Merrilees and J. Robinson-Teran then conducted focused recoding of all the transcripts. Based on this coding, the authors (J. Merrilees and J. Robinson-Teran) identified key themes in the data based on clusters of codes. They met again with the multidisciplinary team to review these themes and theme definitions and share the exemplary quotations that illustrated these themes. They summarized the Qualtrics survey data and identified key themes that were also included in the codebook. Data from the survey were triangulated with interview data to support or add to study findings. Another

author (A. Bernstein Sideman) reviewed the codebook and themes. Three authors (J. Merrilees, J. Robinson-Teran, and A. Bernstein Sideman) then organized the themes according to the overarching domains developed based on the goals of the study. The process was complete when everyone agreed on the thematic domains, definitions, and exemplary quotations.

Findings

Thematic Findings

We organized our findings under three domains: (a) challenges reported by caregivers, (b) Care Ecosystem staff approaches to addressing the needs reported by dyads, and (c) programmatic challenges faced and lessons learned. We assigned each participant a unique number (e.g., Participants 1–9) and linked them with their quotes. An exemplary quotation is provided to illustrate each theme. Table 1 contains additional exemplary quotations that were used in developing the themes. As noted above, two participants served in both clinical and administrative capacities in their programs.

1. Challenges faced by the person with dementia and their caregivers.

    1.1. Fear of exposure to the virus and the risk of illness: Staff reported that many of the dyads were afraid of the possibility of contracting COVID-19. This concern led to reluctance to use medical care and respite services including clinic visits, urgent/emergent care, in-home care, and residential care. Some caregivers who had previously considered long-term care placement chose to delay, or forgo placement out of concern for infection risk and limited visitation/access to the person they were caring for. Those who did pursue placement during this time engaged in extra planning and coordination with the facility to minimize infection risk. There were often tensions among family members who had differing opinions and attitudes about viral exposure risk.

    Participant 2: There were a lot of concerns around whether they should take their loved one to the ED or to the hospital if something came up.

    1.2. Advance care planning: Caregivers expressed concern about having a backup plan for managing the person with dementia's care if they became ill. In many cases, there was no easy solution for who could step in. Some were motivated by the pandemic to review and update advance directives although many were not. Many, for the time being, were no longer considering long-term placement, citing concerns about virus exposure and the inability to visit and take part in care. Finally, funeral planning was a concern when the person with dementia passed away. Caregivers had to decide whether to postpone an in-person service indefinitely or hold a remote service.

    Participant 5: Voluntary placement into a nursing home and long-term care options have definitely been on hold for most of our patients.

    1.3. Limited availability of services and resources and conflicting information: Caregivers who sought respite care and medical services found their options were limited. Most day programs closed indefinitely due to the pandemic; this increased burden for some caregivers while others felt relieved of the pressure to get the person with dementia prepared to attend. There were shortages of incontinence supplies, household products, and groceries as demand surged and production and distribution chains were disrupted. There were challenges in finding credible and current information. Caregivers had difficulty identifying senior shopping hours and figuring out how to obtain COVID-19 testing. Many reported difficulty using technology, accessing the internet, and were often frustrated with delays in receiving information by regular mail.

    Participant 7: The biggest thing that's changed is day programs are off the table and they're not able to offer really anything.

    1.4. Caregiver well-being: Caregivers expressed feelings of loneliness and isolation. Some felt that their ongoing experience of isolation was validated now that others were sharing this experience of being restricted to their homes. Often caregivers did not have specific needs or challenges to report yet they voiced a desire to talk regularly to their CTN. Some were balancing work with caregiving. Many expressed pride in being able to manage during a difficult time. Some caregivers appreciated having contact with family members, for example, grandchildren who provided a welcome distraction.

    Participant 1: Caregivers feel like they're between a rock and a hard place. They might be overwhelmed. They can't place the patient in memory care because of COVID. And then also caregivers are starting to burn out because they don't have the respite or support groups or day programs.

    1.5. Addressing the needs of persons living with dementia: Caregivers reported challenges in juggling a wide variety of concerns that revolved around

Table 1. Domains, Themes, and Exemplary Quotes

Theme	Exemplary quotations
Domain: Challenges faced by the person living with dementia and their caregivers	
Fear of exposure to the virus and the risk of illness	Participant 6: *We have been hearing a lot of caregivers were worried about the person they were caring for getting sick or getting COVID, and then caregivers worried about themselves getting sick, you know, and then who would provide the caregiving?* Participant 4: *I think during that March through May period, everyone agreed that they didn't want to get sick, whether it was real or not. Wherever you are that you didn't want to get sick.*
Advance care planning	Participant 2: *I think it did bring up a good discussion around who would care for your loved one if something were to happen to you.* Participant 2: *They were really concerned that if they placed them, they wouldn't be able to visit.* Participant 8: *Some folks who'd been very resistant to the idea of having a conversation about who would be the caregiver if they got sick and the CTN was able to leverage the situation and ask, "What if you get COVID?"*
Limited availability of services and resources and conflicting information	Participant 4: *They were most concerned about how to juggle everything. And they are trying to figure out what is fake news or what wasn't.* Participant 7: *I feel like everybody has a lot less to offer anybody who doesn't use a computer.* Participant 2: *These were caregivers that worked full time, so they were trying to arrange for in-home care or just trying to make sure that their loved one was taken care of while they were also able to manage their jobs.*
Caregiver well-being	Participant 4: *I would say increase anxiety and stress, of course, at the beginning of not knowing what to do. And I think the trigger point or the source has changed a bit. I think they're still feeling a lot of anxiety, but now it's like uncertainty about how to reengage now in life.* Participant 8: *We even heard from some that they liked it because they felt like finally other people understood what they were going through of feeling tethered to their house. They were like, now everybody gets it.* Participant 9: *There's a loneliness issue and an isolation issue (for the caregivers).*
Addressing the needs of the person living with dementia	Participant 1: *Patients are lonely and isolated. They can't see their family. They can't get out and do group activities.* Participant 7: *I definitely think that change in function has been a result of COVID, both indirectly and directly by our population.* Participant 2: *The patient was having a lot of hallucinations and delusions and it kind of exacerbated during the lockdown because her daughter used to go visit her every day, so, the patient was basically isolated in her room all the time and her room was where she was seeing all of these really distressing delusions. She called 911 a few times because she really thought she was at harm.*
Domain: Care Ecosystem staff approaches to addressing the needs of dyads	
Informational support	Participant 9: *A lot of these families have had the news on all day long. And so I've been telling them, turn off the news, check in in the morning and at night, but you don't have to have it on all day long.* Participant 4: *Build a structure and a routine like they would in adult day or just in life in general.* Participant 7: *I feel like I was paying a lot more attention to where to buy things at first. People are saying, I can't buy diapers. I can't buy wipes. So, finding alternatives.*
Emotional support	Participant 1: *Whenever you feel distant from the medical community and you have someone calling from our office unprompted, that means a lot.* Participant 4: *I've been walking them through different self-care things and different tips that even though you're at home, you can still go outside. You can still breathe the air, look at the sun, watch the clouds, do different mindfulness and grounding exercises, having separate time.* Participant 2: *I think there were some dyads where I could just tell that they really wanted to talk and there might not have been someone else to talk to. I offered more calls to check in, and a lot of them would just reach out directly because I guess they knew I was available and that there was no real disruption in our phone calls.*
Instrumental support	Participant 4: *I also have talked to a lot of people about getting Wander Bracelets in case someone wanders off.* Participant 2: *I feel like people are more open to trying support groups.*
Domain: Programmatic challenges faced and lessons learned	
Technological readiness	Participant 9: *Once our organization accepted use of email to communicate with dyads it opened the door for us to be able to email every two to three weeks.* Participant 8: *I don't have access to a secure printer, so I can't print anything.* Participant 9: *We initially were at the office and then we went into lockdown and had to work from home. That was quite a struggle initially to ensure that that could be done safely and confidentially with participants. And we didn't have the technology or the HR support initially that we needed.*

Table 1. Continued

Theme	Exemplary quotations
Restructured work and adapted workflows	Participant 5: *A lot of our referrals were done through our memory clinic, and it all became virtual. So, the referral stream certainly altered. It just became like phone referrals or messages through EPIC. We also usually did our first visits with the patients in person to kind of build that report, so we had to switch that to also be virtual. Our patients didn't mind, but it always helps to be face-to-face with someone to build that report.* Participant 9: *It helped us to contact people more and then catch up on the annual assessments and really get a better handle on our missing data and serve the people who were in the program better than what we were doing before.*
Program sustainability	Participant 7: *I feel like we get a little bit more invisible because the new fellows come and, you know, it's harder to have a presence in this virtual reality.* Participant 5: *We were probably submitting like four or five grants a year previously, and we just had that one in the past since March. So probably a little bit slower on the grant application side.* Participant 9: *We couldn't hire anybody after staff left because of the hiring freeze of the pandemic.* Participant 5: *Most of our research department was all redeployed to do COVID research … It was just like a couple of weeks, but the CTN and I were redeployed to do COVID research a couple of times during the pandemic.* Participant 3: *A lot of the staff was furloughed, so we ran into a lot less staff members of the clinic.*
Team morale	Participant 9: *This is a crisis for people and for us and for everyone and that we've had to come together to think outside the box and for each other in different ways, then try to figure out how to navigate it together and it seems to me, that's made us a little tighter.* Participant 2: *I also think it's difficult to keep morale high when you're working away from your coworkers, so there are some days which might not feel as productive as others.*
Maintaining continuity of care	Participant 7: *I think our program is really easily adapted. I guess that's the good thing … We didn't have to completely change the way that we work with people.* Participant 1: *I've learned that without the Ecosystem, there's a lot that I don't know. I learned the tip of the iceberg as a clinician and that the number of encounters that have been created through the CTNs involvement, it's just staggering. And it did make more work for me, but it also gave me the satisfaction that nothing was falling through the cracks, that we were connecting on every issue, every psychosocial issue. I really felt that I had a robust program to provide the much-needed support to the community. So, I really feel it's an essential program.* Participant 7: *There is something about having a long-term relationship (with the dyads).* Participant 2: *I feel like it was a perfect model for that because there was really no disruption. It was a pretty seamless transition. I think from working in person to the office to working at home because nothing changed about phone calls.*

the needs of the person they cared for and the challenges created by the pandemic. For example, some people with dementia could not understand or comply with wearing a mask in public or maintaining 6 feet of physical distancing. Staff reported how this created challenges for caregivers who wanted to go out for an activity or run errands together. A major focus for caregivers was finding ways to combat boredom and keep the person with dementia occupied throughout the day. Some caregivers worked to establish a daily routine while others worked to adopt a more relaxed approach to daily activities. Several worried that isolation and reduced engagement in activities contributed to behavioral exacerbations and more rapid decline in function and cognition. Many caregivers reported to their CTNs that they experienced an escalation in problematic behaviors such as repetitive behaviors, aggression and resistance to personal care, depression, sleeping more, not eating, hallucinations, delusions, and wandering. For those residing in facilities, caregivers worried about not being able to visit in-person, thus losing the ability to participate in and influence care.

Participant 7: We heard about change in function, and I think the change in function in most cases was related to having to stay at home or not have visitors.

2. CE staff approaches to addressing the needs of dyads: As noted earlier, we organized the themes that emerged deductively using a social support framework categorized as informational, emotional, and instrumental support. For each of the three categories, we describe the responses about direct dyad interaction and care from the clinical staff (CTNs, registered nurses [RNs], social workers [SWs], physicians [MD]) as well as adjustments made at the programmatic level based on responses elicited from the project managers and clinical staff.

2.1. Informational support:

    2.1.1. CTNs referred to their role as being an "information hub" for caregivers. They reported that caregivers relied on them for information that ranged from valid COVID-19 testing sites to ways to manage patient care issues such as activity and personal care. Caregivers were often curious to find out what others were doing to manage the challenges and the CTN would provide this information if they could. CTNs reported watching the news more often and monitoring their state's Department of Public Health websites to stay current on COVID-19-related information. CTNs coached caregivers on strategies for building structure and routine into the day and stayed current on activities such as online museum tours. Staff provided educational material and coaching on strategies to manage problematic behaviors. In one example, a caregiver was confused at being told the family could not visit the person with dementia who was under hospice care.

Participant 2: One of my caregivers, her mom was started on hospice right when the lockdown was enforced. And they had told her that she was unable to visit. I sent her the CDC guidelines for visitation rights that says that if it's an end-of-life situation, you can, so I remember she showed that to the facility and then they were letting her visit twice a week.

    2.1.2. Programmatically, one site developed a COVID-19 information webpage and recorded a series of webinars offering information relating to pandemic concerns and shared the website widely. Webinar topics included: Having a backup plan in place; in-home activities while sheltering in place; finding resources; staying connected when you have to stay apart; promoting caregiver health and well-being and other topics. Staff also developed an infographic demonstrating strategies for increasing the person with dementia's adherence to COVID-19 mask-wearing mandates. The webinars and other information were posted on a COVID-19-specific website created in response to the pandemic. Another site sent emails and announcements to all dyads to clarify pandemic-related information. One project manager created a protocol for end-of-life care that was shared among the four Care Ecosystem programs to help

ensure there was competence and consistency in the way staff worked with dyads on this issue. The programs held monthly meetings prepandemic, and several staff reported that these meetings were especially helpful during the pandemic, helping to clarify information needs and strategies for meeting dyads' needs.

2.2. Emotional support:

    2.2.1. CTNs and clinical staff provided active listening and emotional support around difficult topics such as potential illness and death. Staff reported having longer than usual phone calls with caregivers struggling with loneliness and isolation. Emotional support was offered around specific events such as not being able to visit residents in facilities, when a COVID-19 outbreak occurred at a facility and being overwhelmed in managing patient-related issues in the home without assistance.

Participant 6: I try to just really provide a lot of reflective listening and empathy and support that this is not an easy decision … And just to really support them on thinking through what's best for their family and how they can feel good about whatever decision that they ultimately made.

    2.2.2. Programmatically, one site, in response to a high number of patient and caregiver deaths, provided referrals to online grief counseling support groups.

2.3. Instrumental support:

    2.3.1. CTNs at some sites made a point to contact all their dyads at the beginning of the pandemic to see how they were managing. They provided guidance about community programs and details such as what programs were open, services offered, and how to access them during the pandemic. CTNs described their efforts in coordinating services for the dyads. They reported focusing a lot of their time on programs and services to help manage social isolation and loneliness. They taught caregivers techniques for calming the person with dementia who was exhibiting anxiety and agitation: techniques included hand massage and relaxing music. CTNs also reported coaching caregivers on strategies to reduce or manage stress related to caregiving. For example, one coached a caregiver to set up

her stationary bicycle next to the television, which allowed her to supervise the person with dementia while exercising. CTNs assisted caregivers with technology, such as Zoom, to ensure they would be able to manage a remote medical appointment and educational webinars.

Participant 3: I will email them or mail them the forms for the health care directive and the power of attorney and then help them with a notary person. We became very creative actually with one … I actually called the bank, and it was possible to do the notary through the drive through in the bank.

  2.3.2. Programmatically, all Care Ecosystem sites collaboratively developed and shared a comprehensive list of activities using google docs. These activities included virtual museum tours, puzzles, nature shows, exercise videos, guided meditation, and arts and crafts. Staff referred to this list to provide ideas for their dyads.

3. Programmatic challenges faced and lessons learned.

 3.1. Technological readiness: Establishing secure methods for contacting dyads when working from home was a struggle for some programs and fairly seamless for others. This often had to do with existing organizational restrictions (e.g., prepandemic, one organization was not allowed to email dyads and relied on telephone or regular mail, but this restriction was eventually lifted). Not every staff person had the necessary technology to work from home, for example, remote desktop access and video calls. Hard copy documents with PHI needed to be printed on secure clinic printers, which was a challenge for CTNs at home.

Anonymous Qualtrics response: It was challenging accessing my computer remotely, and we did not have private/blocked number calling or video visits with Ecosystem participants initially.

 3.2. Restructured work and adapted workflows: For many programs, referrals and thus enrollment slowed initially during this period. Staff used this phase to catch up on work such as data entry and outreach to existing dyads. For some, referral workflows changed from in-person to routing the referral through the electronic medical record. Some programs could no longer conduct their initial assessment in-person with newly enrolled dyads. Care Ecosystem staff in some cases had to rely on clinic staff working in-person for help with printing and mailings. Some staff struggled with adjusting to working from home and they

reported feeling more distracted and that their home space was small or not suited to be an office. Other staff found that they preferred working from home and felt they could focus better and appreciated not having to commute. Most staff reported being able to maintain privacy with PHI in the home environment by keeping notes in an electronic and not paper form or by using headphones during phone calls.

Participant 8: We did manage to work out a whole process where we could send, like the medical assistants in the clinic and ask if they could print this out and mail? But it delays things and is surprisingly inconvenient.

 3.3. Program sustainability: Some programs experienced barriers to sustainability efforts. For example, grant deadlines were missed and efforts to implement new billing mechanisms were stalled as administrative operations were disrupted and/or diverted to pandemic-related work. Some of the staff were concerned that their program was less visible to referring providers due to working remotely. Staff layoffs and furloughs had varying impacts on the Care Ecosystem programs. One program gained a clinical staff member who was furloughed from another department. Another program was poised to hire an additional CTN but lost the opportunity when their organization implemented a hiring freeze.

Participant 5: We were looking at having new grants submitted and hiring another care team navigator, but that was kind of all put on hold.

 3.4. Team morale: Most staff reported feelings of gratitude to be engaged in meaningful work. Some reported feeling closer as a team. Staff described the necessity of relying on each other to work out solutions to problems the dyads were experiencing. Some staff reported they were able to feel "connected" with other team members while others reported difficulty in maintaining connection while working remotely.

Participant 9: Having to overcome this has also brought us a little bit closer.

 3.5. Maintaining continuity of care: The ability to maintain a connection with dyads is a strength of the Care Ecosystem that existed prepandemic and this was noted by many of the staff in their interviews. Because the program is built on a telephone-based model of support, connection with dyads continued largely uninterrupted during the pandemic. CTNs provide longitudinal

support and gain useful knowledge about their dyads' values, preferences, resources, and needs. They leveraged this knowledge to personalize care during the pandemic.

Participant 1: I don't feel like anyone is falling between the cracks.

Discussion

Through interviews with staff from four Care Ecosystem programs in four states, we identified common concerns of persons with dementia/caregiver dyads during the first 3 months of the COVID-19 pandemic, how the programs responded and adapted during this phase to optimize support for dyads under their care, and the programmatic challenges faced. Consistent with prior reports, caregivers were concerned about infection, loneliness, social isolation, increased stress, service disruptions and reduced access to supplies, resources, and medical and nursing care (Lightfoot et al., 2021; Parmar et al., 2021; Tam et al., 2021). Those providing care at home reported not being able to get a break from caregiving responsibilities. Reports of worsened behavior symptoms, reduced appetite, and more rapid functional decline of the person with dementia were common. Changes in routine, boredom, lack of physical and social activity, loneliness, and others' emotional distress contribute to these kinds of negative outcomes (Kales et al., 2014), and it is not surprising that these concerns emerged during the early phase of the pandemic.

We identified collaborative and creative ways that the Care Ecosystem teams responded to the needs of their dyads. Staff increased the frequency or duration of calls to support isolated caregivers and they worked together to find and share up-to-date information and resources in a rapidly changing landscape. They collected a variety of practical in-home activity ideas, produced a free educational webinar series, shared tips, and strategies for improving compliance with masks among people with dementia, helped caregivers learn to use new technology, and facilitated advance care planning. This emphasis on building long-term relationships has been paramount in the success of dementia-capable models of care (Evertson et al., 2021; Mok et al., 2020) and is a key feature of the success of the Care Ecosystem in responding to needs brought on by the pandemic. The program was not able to fully address some of the gaps in essential respite care services, like day programs and in-home care services, that help alleviate the burden of care on family caregivers. Nonetheless, as the early phase of the pandemic unfolded, program staff stayed connected with dyads, navigated access to information and resources, and provided support to ease the stress of facing a time of unprecedented challenges. Finally, it has been shown that caregivers fared better if able to identify positive aspects of the pandemic (Savla et al., 2021), and the

CTNs fostered this type of reframing. For example, some caregivers noted positive outcomes that resulted from the pandemic such as avoiding stress associated with bringing the person with dementia to in-person appointments or acknowledgment of their ability to cope during this distressful time.

Programmatic strengths of the Care Ecosystem were revealed as a result of the pandemic. This program was originally designed as a remote telephone- and web-based care model to maximize accessibility and cost-efficiency. This feature allowed most sites to continue care delivery with minimal disruption, though there were some initial challenges with limited technological resources and institutional policy barriers at some sites. With the pandemic came a reliance on telehealth and video visits (Feder et al., 2021; Quach et al., 2021), and this was relatively easy for many dyads but more complicated for others that lacked the infrastructure or skills. Staff may need training in order to support their dyads (Nearing et al., 2020), and as our study showed, many CTNs often coached dyads on how to use technology for upcoming medical appointments. Care Ecosystem staff were able to leverage relationships within their health systems to overcome staff shortages during a hiring freeze and to help with occasional on-site tasks like mail, fax, and scanning. Collaboration within and across sites enhanced care delivery by expanding the collective knowledge base and social support network. Teamwork and partnerships are essential to the safety and well-being of older adults (Franzosa et al., 2021), and the collaborative team-based care is another foundational principle of this model that proved useful during the pandemic.

In summary, we identified concerns of the person with dementia and their caregivers, including fear of virus exposure and illness, concerns about functional decline and behavioral symptoms of the person with dementia, access to information and resources, changing attitudes toward long-term care, and loneliness and isolation. CE programs, by virtue of an established structure of telephone contact with dyads, were able to maintain a connection with dyads relatively easily. CE staff demonstrated flexibility and creativity in responding to the dyads' needs and providing informational, emotional, and instrumental support. Barriers that CE programs encountered were often due to technological and institutional restrictions that impeded communication with the dyads, which improved as barriers were lifted. Personnel, staffing, and financial support through grant funding were often interrupted during this phase of the pandemic. Lastly, we found that much of the success of the CE programs during this time was due to leveraging strong partnerships within their organizations and their communities in both information sharing and management of workflow.

Limitations

Our interviews were conducted with staff and not with the dyads; therefore, our findings may not accurately represent

their concerns or the usefulness of the interventions; however, our results are consistent with other research conducted with older adults and caregivers (Kotwal et al., 2021; Tam et al., 2021). The relatively small number of participants interviewed reflects the status of the Care Ecosystem diffusion into practice, as the model is currently only being implemented by a limited number of health systems and is not broadly available. More work is needed to understand potential regional and demographic differences.

Conclusion

Results from this study can help to inform how programs that care for people with dementia and their caregivers can respond to unexpected events that threaten public health and safety. People with dementia, by virtue of the impact the disease has on their function, cognition, and behavior, and caregivers, who shoulder complex challenges involved in providing care, are vulnerable even in the best of times. Unexpected events at the scale of natural disaster or public health crisis adds disproportionate burden to these groups. The findings from this study help to identify the unique challenges faced by dyads during the initial stages of the pandemic and provide an important mechanism for understanding how dementia care programs can be positioned to offer continuous support for this especially vulnerable population.

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Conflict of Interest

None declared.

Author Contributions

J. Merrilees, J. Robinson-Teran, and A. Bernstein Sideman planned the study, supervised data analysis, and wrote the article. M. Allawala, S. Dulaney, and K. L. Possin contributed to the planning of the study and data analysis. S. Dulaney, M. Rosenbloom, H. D. Lum, R. J. Sawyer, and K. L. Possin contributed to data evaluation and revisions of the article.

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