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## A Program to Improve the Quality of Life of Caregivers of Older Adults with Chronic Conditions: A Pilot Study

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## A Program to Improve the Quality of Life of Caregivers of Older Adults with Chronic Conditions: A Pilot Study

### Abstract

*Background:* Among the nearly 41.8 million family caregivers of older adults 50 years of age and older in the United States, only 30% of caregivers report receiving the education, resources, and support they need to feel competent in their role. Many existing programs focus on dementia-related caregiving, and programs are needed to address the caregiving needs of individuals with chronic conditions.

*Method:* A pilot study using a mixed methods design was conducted with eight participants. The pre and post measure, Adult Carer Quality of Life (AC-QoL), and post program individual interviews were conducted.

*Results:* Six of the eight AC-QoL subscales showed improvement in quality of life and two showed decreases. The effect size was 0.63 for the total AC-QoL score, requiring 25–30 participants to achieve a power of 0.80 in a larger study. Interview data indicated the program provided an outside perspective of caregiver needs, provided information, resources and a support system, reduced their stress, and improved self-efficacy.

*Conclusion:* Further study of programs for caregivers of older adults with chronic conditions are important to fully address the needs of 35 million unpaid caregivers. Occupational therapists are ideally situated for leading the development of such programs given their unique practice focus and expertise.

### Keywords

caregiving, caregiver program, caregiver needs, care coordination, occupational therapists

### Cover Page Footnote

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### Credentials Display

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Nearly 41.8 million family caregivers in the United States provide unpaid care to individuals 50 years of age and older (National Alliance for Caregiving & AARP Public Policy Institute, 2020). The population of older adults is projected to double over the next 40 years as people continue to live longer (Roberts et al., 2018), which will markedly increase the number of individuals requiring caregiver assistance. Of the population of caregivers, 36% provide care to someone with dementia, and the rest provide care to older adults with various chronic conditions (Family Caregiver Alliance, 2019). The average age of caregivers for older adults is 59 years; 60% are female, and 40% are male (Reinhard et al., 2008). The majority of assistance is provided for activities of daily living (96%) and assistance with instrumental activities of daily living, such as mobility (75%), grocery shopping (76%), housework (72%), and transportation (78%) (Alzheimer's Association, 2020; Family Caregiver Alliance, 2019; Riffin et al., 2017).

### **Challenges of Caregiving**

For home-based and community-based services provided by Medicaid, only 30% of states include an assessment of caregiver needs (Kelly et al., 2013). In the health care system, only 30% of caregivers report receiving the support they need (Reinhard et al., 2008). Support is especially important after a health event when care recipients transition from a hospital or health care setting to home, but health care providers lack understanding or coordination about who is responsible for providing transitional care services (Jeffs et al., 2017). Physicians and other health care providers typically do not ask about the needs of caregivers or assess their ability to provide care. As a result, caregivers do not feel they have the education and training to complete their role effectively during the transition of their loved one from a health care setting to home (Reinhard et al., 2008). Caregivers have reported needing more information to feel competent in their role, such as knowledge of available resources; an ongoing assessment of their needs; and psychosocial, spiritual, and financial support (Bell et al., 2019). They also want a team approach to service provision and would like to be included in the development of caregiver guidelines and best practices (Bell et al., 2019).

Although caregivers may know resources are available to them, they often do not know where to find them. Further, they do not have time to search for information or know which services or resources would be helpful for their situation (Bacon et al., 2021). Affordability may be another reason caregivers do not use available resources. Respite and other services are fee-based, and many middle-income families cannot afford the range of services needed and do not qualify for government-subsidized programs (Bookman & Kimbrel, 2011). Other reasons for not using services are a lack of awareness of availability, being uncomfortable with an unknown person in the home, and difficulty finding qualified care assistants (Casado et al., 2011).

These challenges, the inability to secure services, feeling unsupported, and lacking the required education and training to fulfill responsibilities effectively, result in a great deal of stress for caregivers. Four in 10 caregivers report a high level of emotional stress because of their caregiving responsibilities, and more than 50% of those care for someone with dementia (National Alliance for Caregiving & AARP, 2020). Because caregiver stress is related to an individual's self-efficacy, lower self-efficacy results in higher stress levels (Hampton & Newcomb, 2018; Yang et al., 2019). With consistent levels of stress, the risk for mental and physical health problems increases. Vitaliano et al. (2003) found a 9% greater risk of health problems among caregivers than non-caregivers, with an increased risk for illness, hypertension, and diabetes. Mental health concerns reported by caregivers include depression, anxiety, guilt, and

emotional strain, all of which occur at much higher rates than those of non-caregivers (Family Caregiver Alliance, 2019; Lewin Group, 2016; Poo & Whitlatch, 2017).

### **Addressing Caregivers' Needs**

Given the prevalence of stress among caregivers, the increased risk for corresponding physical and mental health problems, the lack of desired education and skills training, and the lack of a coordinated health care effort to address caregiver needs, evidence-based programs are needed to support caregivers. In 2021, the the federal government recognized the importance of addressing caregivers' needs with their allocation of \$145 million to the Older Americans Act programs as part of the American Rescue Plan (The White House, 2021). With federal funds, each state's Area Agency on Aging can deliver caregiver programs with information such as community resources and services, support groups, counseling, and caregiver training (Administration for Community Living, 2021; The White House, 2021).

Although federal funding is beneficial for addressing caregivers' needs, it primarily focuses on individuals of lower socioeconomic status. Because the Area Agency on Aging programs are based on financial need, individuals and families receive greater stipend amounts for services and support when they are of lower income (Area Agency on Aging Region One, 24-Hour Senior Help Line, personal communication, February 10, 2021). Middle income individuals receive little to no stipend for these services, which makes it difficult to pay for services that benefit caregivers.

### **Community-Based Programs**

In addition to state agencies, several community-based programs have been developed to address the needs of caregivers, many of which are specific to caring for individuals with dementia. One such program is the nationwide program Resources for Enhancing Alzheimer's Caregiver Health (REACH). It is a 6-month program with trained coaches who provide caregivers with skills, tools, and information to address the challenges and needs of caregiving for an individual with Alzheimer's dementia (Family Caregiver Alliance, 2020). The program was first implemented in the U.S. Department of Veterans Affairs as the Resources for Enhancing All Caregivers Health (REACH VA) program to address the needs of caregivers of veterans with chronic health conditions and was shown to reduce caregiver burden and stress and improve social support (Gitlin et al., 2006). A study of the REACH program involving dementia caregivers found significant improvements in caregiver depression, burden, and self-efficacy; caregivers also had less anxiety about their care recipients' behavior and memory problems (Czaja et al., 2018). Similar results to REACH were found in two other studies of programs for dementia caregivers that offered educational information and resources, with one program including immediate online assistance. The results were reduced caregiver burden and depression and improved self-confidence, self-efficacy, and satisfaction. (Núñez-Naveira et al., 2016; Terracciano et al., 2020).

### **Programs Developed by Occupational Therapists**

In a systematic review of programming for dementia caregivers, evidence from five randomized controlled trials suggested that occupational therapy sessions providing caregivers with education, problem-solving, and technical skills (task simplification, communication) and simple home modifications improved patient skills, decreased their need for assistance, and reduced behavioral occurrences among the individuals with dementia (Thinnes & Padilla, 2011). One of the programs in this systematic review (Thinnes & Padilla, 2011) was the Environmental Skill-Building Program (ESP), originally developed in agreement with REACH. In ESP, occupational therapists complete five home visits over 3 months, where the therapist works with the caregiver to identify care-recipient behaviors that are difficult to manage and provides strategies to manage the behaviors by manipulating objects, tasks,

and elements of the sociocultural environment. In addition, ongoing education and information about support groups and community resources are provided (Corcoran & Gitlin, 1992). Studies of ESP found that the education, problem-solving, skills training, and home modifications decreased care-recipient assistance and reduced care-recipient behaviors (Gitlin et al., 2005). Results for the caregivers were that they felt more confident and gained a better sense of control when provided with coping strategies (Graff et al., 2006, 2007). Another program developed by occupational therapists is Caregiver Options for Practical Experiences (COPE) (Miller & Butin, 2000). In this group-based program, therapists empower caregivers with effective problem-solving strategies to engage the care-recipient in self-care and leisure activities in keeping with care-recipient strengths and interests, thus promoting positive behavioral change. In the COPE program, care recipients had less functional dependence and improved engagement, and caregivers showed improved well-being and confidence using activities to engage the care recipient (Gitlin et al., 2010).

Research on programs for dementia caregivers suggests similar benefits may be found for caregivers of individuals with other chronic progressive conditions (Czaja et al., 2018; Gitlin et al., 2005, 2006, 2010; Graff et al., 2006, 2007; Terracciano et al., 2020). The literature confirms that programming for caregivers should include information about affordable resources, support, education, and skills training and that this information should be tailored to a specific caregiver's needs to be most beneficial (Bell et al., 2019; Poo & Whitlatch, 2017). In addition, access can be enhanced by offering caregivers telephone or computer-based consultation, recommendations, and progress monitoring (Thinnes & Padilla, 2011).

### **Home-Based Care Coordination Program**

Given the research to support programs for dementia caregivers, studies are needed that assess the feasibility and outcomes of programs to address the needs of caregivers of individuals with other chronic conditions. Allied health professionals are a valuable resource for addressing caregiver needs because they are already in contact with them through their patients. However, in the confines of traditional practice and reimbursement, therapy services are restricted to those directly associated with the patient's skilled needs, leaving the caregiver's needs not fully addressed and ancillary to the client. With a community-based mindset, occupational therapists are well-qualified to comprehensively target caregivers' specific needs. Guided by ecological theories, occupational therapists have a unique understanding of the interactions of person, environment, and task and its influence on the effective function of the caregiver-care-recipient dyad and on optimal co-occupational performance.

Informed by the REACH and ESP programs, a home-based care coordination program called CarePLaCe was developed by occupational therapists to fully meet the needs of caregivers, including those caring for older adults with chronic health conditions. Given the lack of research on this type of program, a pilot study was conducted to assess the feasibility of CarePLaCe and to inform the sample size needed for an intervention study. The specific aims of the current pilot study were to evaluate changes in caregiver quality of life using the Adult Carer Quality of Life Questionnaire (AC-QoL) before and after the CarePLaCe program, to assess caregiver perceptions of the effectiveness of the program using individual interviews and the effectiveness of recruitment strategies, and to evaluate effect sizes and complete a power analysis for optimal sample size in a larger study.

## Method

### Study Design

The current pilot study used a mixed-methods design that included a quantitative outcome measure using the AC-QoL before and after the CarePLaCe program and qualitative data from individual interviews. The participants were caregivers aged 18 years of age and older living with and caring for an individual aged 60 years of age and older with a chronic condition, including dementia. Participants had to be residents of Arizona and have adequate technology to participate in the study using a telehealth platform. The pilot study used telehealth instead of in-person interactions to meet required COVID-19 safety measures. The Internal Review Board of A. T. Still University approved the study.

### Participants

The participants of the current pilot study were recruited through community partner agencies in the Phoenix metropolitan area, including Aster Aging, Arizona Caregiver Alliance, and Neighbors Who Care. Because these agencies were barely operational because of the COVID-19 pandemic, an amendment to the recruitment strategy was approved to include presentations at community support groups and expansion of the recruitment region from a metropolitan region to the entire state. With the amendment, the participants were also recruited through presentations by study researchers at various community organizations and support groups. Eligible participants were provided information about the program and pilot study, and informed consent was obtained by mail or in person. Twelve caregivers consented to participate in the pilot study, and eight completed the CarePLaCe program, the preprogram, and post program AC-QoL measures, and the follow-up interviews.

### Procedures

After providing consent, the participants had a needs assessment and a home assessment, if desired, performed. They also attended a care plan review meeting and individualized education and training sessions. The needs assessment included structured questions to obtain background information and understand the participant's caregiving circumstances, environmental demands, and caregiver needs. In addition, the Canadian Occupational Performance Measure [COPM] (Law et al., 1990; Toomey et al., 1995) was administered to assess areas of need based on the caregiver's perception of the quality of their caregiving and satisfaction with assisting the care recipient in daily occupations. The COPM was also used by Graff et al. (2007) to evaluate the occupational performance of caregivers and care recipients with dementia. This assessment uses a 10-point scaled score to measure effectiveness and satisfaction in the performance of caregiving responsibilities, where 1 is rated as the least satisfied and lowest quality of performance, and 10 as the highest. Next, the caregivers completed the preprogram quality of life questionnaire, the AC-QoL (Joseph et al., 2012). During the needs assessment, the recommendation for a home assessment was discussed with the caregiver and scheduled as needed.

After obtaining all the information from the needs assessment, an individualized care plan was developed that incorporated community resources and services, recommended home modifications and adaptive equipment, and provided online education and skills training modules targeted to the caregiver's needs. Resource information and education were focused on subscale scores of the AC-QoL that indicated mid-to-low range quality of life (scores 0–10). Educational modules included home safety and modification, transfer and mobility training, medication management, caregiver stress and self-care, and three separate modules on dementia. CarePLaCe was designed to be delivered in person, but because of required COVID-19 safety measures, all program elements were implemented using a Health Insurance Portability and Accountability Act compliant telehealth platform. The length of program participation

varied according to the number of education and skills training modules needed and the participants' health status and availability. Program length was also determined by whether home modifications had to be completed. After the program, the caregivers completed the post program AC-QoL and an individual interview to provide program feedback. The interviews were completed through the telehealth platform.

### **Instruments**

The AC-QoL (Joseph et al., 2012) was used to address the study's aim of evaluating change in the quality of life as a result of participating in the CarePLaCe program. This questionnaire is a 40-item assessment that uses a scaled score to measure the current degree of certain elements of caregiving. Joseph et al. (2012) established convergent validity and internal consistency of 0.95 for this instrument. Possible responses for each item are never to always and are scored from 0–3, depending on whether the item is positively or negatively worded. The total score ranges from 0–120, and higher scores indicate a greater quality of life. The assessment is divided into eight subscale areas: support for caring, caring choice, caring stress, money matters, personal growth, sense of value, ability to care, and carer satisfaction. Each subscale has a possible score of 15, with 11–15 indicating a high quality of life for that subscale, 6–10 indicating mid-range quality, and 0–5 indicating a low quality. This questionnaire was converted into a survey using Qualtrics<sup>XM</sup> with permission provided by the AC-QoL developers (Joseph et al., 2012). The participants were provided with a link and a password to access the questionnaire for both pre and postprogram completion. Surveys were kept within Qualtrics<sup>XM</sup> until time for data analysis.

The current pilot study aim of assessing caregiver perceptions of program effectiveness informed the interview questions. Individual interviews were conducted after program participation and consisted of structured questions that assessed the effectiveness of CarePLaCe program elements in meeting caregiver needs. Specifically, the interview questions included the following:

1. How was the care plan created for you beneficial to improving your caregiver experience?
2. Tell us about any information that was not covered in the educational sessions that you feel would have been helpful.
3. What suggestions do you have for how we might improve any portion of the CarePLaCe program?

During and after the interviews, participant responses to the interview questions were typed by the study researcher. Immediately after each interview, notes were reviewed, and additional information was added by the researcher to ensure complete information was captured. The typed interview responses were kept on a password-protected share drive, with access only by the primary investigator and three co-investigators.

### **Data Analysis**

Data from the AC-QoL Qualtrics<sup>XM</sup> surveys were converted into an Excel file for analysis and determination of trends from preprogram to post program participation. Only numerical data were included in the Excel file with no participant identifying information. Descriptive statistics (i.e., means, standard deviations [*SD*]) were calculated for these outcome measures. A paired-samples *t* test was used to compare AC-QoL scores before and after the program, and effect sizes were calculated using Cohen's *d*. Estimates of data variability and effect sizes were conducted to determine the optimal sample size for a larger study. The statistical software SPSS ver 28 (IBM Corp., Armonk, NY) was used for all analyses, and a  $p < .05$  was considered statistically significant.

Data from individual interviews were analyzed in two ways. First, responses to the structured interview questions were analyzed for the study's aim of assessing caregiver perceptions of program

effectiveness. Second, themes in interview responses were developed. To analyze perceptions of effectiveness, the primary investigator and three co-investigators each reviewed responses to interview questions among all participants. Common responses to questions among all the participants were established by each investigator. The primary investigator then reviewed and compiled common responses among all investigators. For the development of interview themes, the primary investigator and co-investigators each analyzed and hand-coded the responses to interview questions for each participant and established themes among all the participants. The primary investigator then analyzed these themes among the investigators to establish common themes (Guest et al., 2012). The development of themes by four investigators provides investigator triangulation of the data, reducing bias in the analysis and improving validity (Moon, 2019).

### Results

Four of the 12 participating caregivers stopped participating after the care plan was developed and reviewed with them. Three of these caregivers reported they did not feel a need for the education modules, and they were unresponsive to emails requesting completion of the postprogram AC-QoL and scheduling of the interview. For one of these caregivers, the care recipient had declined and died a couple of months later. Therefore, the full CarePLaCe program was completed by eight participants.

When evaluating changes in caregiver quality of life before and after the program, six of the eight AC-QoL subscales showed improvements in quality of life, and two showed decreases. Table 1 presents the results of comparisons between preprogram and post program AC-QoL scores. The mean (absolute) effect size was 0.79, and the effect size for the total scale score was  $-1.08$ .

**Table 1**

*Comparisons of the Adult Carers Quality of Life Questionnaire (AC-QoL) Scores Before and After the CarePLaCe Program*

AC-QoL Subscale	Preprogram	Postprogram	<i>p</i>	Effect Size
	<i>M (SD)</i>	<i>M (SD)</i>		
Support for caring	8.00 (3.55)	10.75 (2.43)	.01*	-1.19
Caring choice	4.75 (2.19)	3.25 (1.67)	.13	0.61
Caring stress	4.50 (3.07)	2.75 (1.83)	.12	0.62
Money matters	7.63 (1.41)	8.50 (0.93)	.09	-0.70
Personal growth	7.50 (3.85)	9.88 (2.85)	.09	-0.69
Sense of value	10.13 (5.14)	13.38 (2.00)	.13	-0.61
Ability to care	10.13 (2.64)	12.38 (1.77)	.02*	-1.06
Carer satisfaction	6.88 (2.10)	8.63 (0.74)	.047*	-0.85
Total score	59.50 (13.90)	69.50 (7.11)	.02*	-1.08

*Note.* A paired-samples *t* test was used to compare preprogram and post program AC-QoL scores. Effect size was calculated using Cohen's *d*.

\*A *p* < .05 was considered significant.

Two of the eight categories, caring choice and caregiver stress, did not improve post program participation. The lack of stress reduction contradicts previous studies of similar programs for caregivers (Czaja et al., 2018; Gitlin et al., 2005, 2006, 2010; Graff et al., 2006, 2007; Terracciano et al., 2020). However, only five of the 40 items of the AC-QoL assess stress, which may explain this finding. Previous



studies used other measurement tools that specifically assessed the burden of care and stress (Czaja et al., 2018; Gitlin et al., 2006; Terracciano et al., 2020). Therefore, a more in-depth assessment of stress may have found a change in stress after the program. The lack of improvement in caring choice may be explained by the additional awareness of caregivers as a result of previously completing the AC-QoL and finishing the program. For example, the education, skills training, and resources provided in the care plan may have reinforced their role and responsibilities as a caregiver without affecting their choice of being a caregiver. Although choice may be related to overall quality of life, it may be difficult to effect a change through participation in programs designed to help caregivers carry out their role.

Qualitative analysis of caregiver perceptions of the effectiveness of the CarePLaCe program indicated most participants had positive perceptions. A thematic analysis of the interviews found five themes: the benefit of an outside perspective, needed information and resources provided, having a support system, reduced stress, and improved self-efficacy. The caregivers reported the CarePLaCe program provided an outside perspective that was beneficial in providing insights about previously unaware of needs and prompting them to make needed changes. The participants indicated that the information delivered during the initial needs assessment helped them to be more aware of and open to assistance and resources. The individualized care plans highlighted information and resources that were targeted to specific needs of each participant and motivated them to make positive changes, which some of the participants reported improved their health and safety. Some of the participants reported the information from the home assessment was helpful safety information that was simple and easy to implement. Information provided about community resources was a valuable and effective part of the CarePLaCe program, which one participant noted as the “biggest help” for their family, and others reported reduced their stress. Although the post program AC-QoL scores did not show a reduction in stress, several of the participants reported stress reduction achieved through validation of knowledge and care strategies, having someone (an occupational therapist) to contact, and through a reduction in fear. The participants indicated the program was an important support system rather than simply a list of resources. One participant indicated the program “feels like a lifeline” promoting positive changes and support so “I no longer feel alone.” Finally, the participants reported changes in self-efficacy as a result of the program, indicating greater confidence and an improved outlook about providing care. Example quotes related to identified themes are reported in Table 2.

When asked about recommended changes to improve the program, the caregivers suggested additional areas of information about alternative living options, helpful hints on cooking and doing laundry (reported by a male caregiver), information on do not resuscitate and power of attorney, and basic information on Medicare versus Medicare Advantage plans. Three of the caregivers reported they would have preferred the program to be delivered in person. One caregiver suggested providing a written description of the recommended education modules, in addition to the verbal description, during the care plan review and a more explicit and advanced notice of the end date for the program. In a larger study of the CarePLaCe program, caregiver recommendations for additional information, a description of recommended educational modules, and a timeline for program participation should be included. Since some of the caregivers reported they would have preferred in-person delivery of the CarePLaCe program, perhaps caregivers in the larger study should be given a choice of type of participation (in-person or virtual). Comparisons between outcomes for these two intervention groups may provide useful information to understand if the type of delivery influences outcomes.

**Table 2***Example Quotes from Participant Interviews by Identified Themes*

<b>Identified Theme</b>	<b>Example Quote</b>
Benefit of an outside perspective Needed information/resources provided	“Having an outside perspective pushed us forward a bit and helped us be open to making changes.” “CarePLaCe is a like a library of books with information that I can access whenever needed.”  “Provided information they had not thought about and changes for safety and performance that were simple, straightforward, and easy to implement.”
Having a support system	CarePLaCe is like “having a support system that provides reliable information that motivates change.” “Just knowing that CarePLaCe is there and that I am not alone.” “Knowing that CarePLaCe is available for me has been very beneficial.”
Reduced stress	“Having the information ahead of time reduces my stress.” “It definitely reduces my stress knowing that the resources are available when I need them and don’t end when I’m done with the program.” “I feel less stressed because I know I have you [occupational therapist] to contact if I need assistance.” “The fears I didn’t know I had are reduced.”
Improved self-efficacy	“Things have gotten better as I’ve gotten more experience doing tasks.” “Caregiving is an ever-evolving process, and I am continually learning based on information provided in the care plan.” Participating in the program provided “validation and affirmation of things that I knew or was already doing.”

*Note.* Any grammatical errors in the data are a result of direct quotes from the participants.

The aim of assessing the effectiveness of recruitment strategies for a larger intervention study was not met. Our initial reliance on recruitment from community partner agencies proved challenging and required expanding recruitment, as also noted by Leslie et al. (2019). While recruitment was expanded, the lack of operability of agencies and support groups because of the pandemic continued to prove challenging to our recruitment efforts. Recruitment also appeared to be affected by the consuming daily challenges of caregiving. It was evident when speaking to potential participants during recruitment that caregivers were overwhelmed. Finding time in their day to participate in the current pilot study appeared to be challenging for some. A few potential participants were in tears when describing their situation and its challenges. Despite the known potential benefits, a couple of caregivers stated that they just could not add something else to do (e.g., participation in the study).

Although recruitment was challenging, we could evaluate effect sizes and complete a power analysis for optimal sample size in the larger study. Using the suggestion of Browne (1995), the upper limit of the 80% confidence interval for the pilot study’s *SD* was used to calculate sample size. The effect size was 0.63 for the total AC-QoL score, requiring 20 participants to achieve a power of 0.80, two-tailed. Allowing for a loss to follow-up of 20%–30%, 25–30 participants should be enrolled in the larger study.

### **Discussion**

The overall purpose of assessing the feasibility of conducting an intervention study of CarePLaCe was met. The results of the current pilot study seemed to meet three of the four original aims, which were intended to inform a larger intervention study. Changes in AC-QoL scores from preprogram to post program participation showed improvement in six of eight quality of life areas. The caregiver perceptions of program effectiveness, and additional elements to include in the program, were reported in individual interviews. Effect sizes and a power analysis were completed to determine an optimal sample size in a larger study.

The fourth aim of determining recruitment effectiveness was not achieved despite recruitment changes implemented during this pilot study. The recruitment strategies used and others suggested by Leslie et al. (2019), such as use of social media, may prove beneficial in a larger study. Recruitment will

also likely be more effective post-COVID-19 safety measures when agencies and groups are more fully operational. The lack of improvement in AC-QoL sub-scale scores for caregiver stress may indicate five questions related to stress is ineffective, and a more in-depth assessment may be needed in a future intervention study of CarePLaCe. Perhaps the Zarit Burden Interview used by Gitlin et al. (2006) and Czaja et al. (2018) or the Kingston Caregiver Stress Scale (Sadak et al., 2017) could be used. A more in-depth assessment could more accurately measure the ability of the CarePLaCe program to reduce caregiver stress, which is a common outcome of caregiving. Consistent with prior research, the caregivers in this pilot study felt they were provided with much-needed resource information during the program, which is a key area of need reported in the literature (Bacon et al., 2021; Bell et al., 2019; Reinhard et al., 2008). The caregivers in this study were also provided with a support system and improved self-efficacy, which is consistent with prior studies (Czaja et al., 2018; Gitlin et al., 2005, 2006, 2010; Graff et al., 2006, 2007; Terracciano et al., 2020).

### Implications

For future implementation and study of the CarePLaCe program, the participants recommended additional areas of information to include, such as information on alternative living options, cooking and doing laundry (reported by a male caregiver), do not resuscitate, power of attorney, and basic information on Medicare versus Medicare Advantage plans. Some participants in this pilot study indicated they would have preferred an in-person program. Therefore, future implementation of CarePLaCe might include an in-person option. With this additional option, an intervention study could include two intervention groups, one virtual and one in person, and compare results from the two methods of program delivery. Listening to and implementing participants' suggestions for additions and changes to the program are important to fully addressing caregiver needs and to the effectiveness of the program. Caregivers have reported they want to be included in the development of caregiver guidelines and best practices (Bell et al., 2019).

### Conclusion

The caregiver program of the current pilot study, CarePLaCe, and other programs for caregivers of individuals with dementia, such as REACH and ESP, provide caregivers with much needed and desired education and skills training, community resource information, and environmental changes that improve caregiver quality of life. In such programs, caregiver needs are no longer simply ancillary to the client with skilled needs. To fully address the needs of the nearly 41.8 million unpaid caregivers in the United States, further study is needed of caregiver programs for those caring for older adults with chronic conditions and dementia. Guided by ecological theories, occupational therapists are ideally situated for leading the development of such programs given their unique practice focus and expertise in assessing the individual and the individual's tasks and environment and by providing recommendations that promote the safety and independent performance of daily activities for the caregiving dyad. By using this systems approach to address the needs of caregivers and their care recipients, occupational therapists are well-positioned to address the needs of caregivers and improve the quality of life for the caregiver-care-recipient dyad.

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