Caregiver Outcomes of a Dementia Care Program

Leslie Chang Evertson[a], **Lee A. Jennings**[b], **David B. Reuben**[c], **Kassandra Zaila**[d], **Nadia Akram**[e], **Tahmineh Romero**[f], **Zaldy S. Tan**[g]

[a]Alzheimer's and Dementia Care Program, Department of Geriatrics, University of California, Los Angeles 200 UCLA Med Plaza #365A Los Angeles, CA 90095, United States of America

[b]Reynolds Section of Geriatrics, Department of Medicine, University of Oklahoma Health Sciences Center 1122 N.E. 13th Street, ORB 1200 Oklahoma City, OK 73117, United States of America

[c]Multicampus Program in Geriatric Medicine and Gerontology, David Geffen School of Medicine, University of California, Los Angeles, CA 90095, United State of America

[d]David Geffen School of Medicine, University of California, Los Angeles, 10945 Le Conte Ave. Suite 2339 Los Angeles, CA 90095, United States of America

[e]Multicampus Program in Geriatric Medicine and Gerontology, David Geffen School of Medicine, University of California, Los Angeles, CA 90095, United State of America

[f]Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine, University of California, Los Angeles 911 Broxton Avenue Los Angeles, CA 90095, United States of America

[g]Jona Goldrich Center for Alzheimer's and Memory Disorders, Department of Neurology, Cedars-Sinai Medical Center, 127 S. San Vicente Blvd, A6600, Los Angeles, CA 90048, United States of America

Abstract

The University of California, Los Angeles Alzheimer's and Dementia Care (ADC) program enrolls persons living with dementia (PLWD) and their family caregivers as dyads to work with nurse practitioner dementia care specialists to provide coordinated dementia care. At one year, despite disease progression, overall the PLWDs' behavioral and depressive symptoms improved. In addition, at one-year, overall caregiver depression, strain, and distress related to behavioral symptoms also improved. However, not all dyads enrolled in the ADC program showed improvement in these outcomes. We conducted a mixed qualitative-quantitative study to explore why some participants did not benefit and what could be changed in this and other similar dementia management programs to increase the percentage who benefit. Semi-structured interviews (N=12) or surveys (N=41) were completed with 53 caregivers by telephone, mail and

Corresponding author: Leslie Chang Evertson, DNP, RN, GNP-BC, levertson@mednet.ucla.edu, 112 Glendon Court Simi Valley, CA 93065, 805-907-1250.

online. Seven areas for potential program improvement were identified from the first 12 interviews. These included: recommendations that did not match caregivers' perceived care needs, barriers to accessing care and utilizing resources, differing care needs based on stage of dementia, needing services not offered by the ADC, needing more education or support, behavioral recommendations that the caregiver felt did not work, and poor rapport of the dementia expert with caregivers. Despite having been identified as having had no clinical benefit from participating in the program, most caregivers (85%) reported that the program was very beneficial or extremely beneficial. Respondents identified the close, longitudinal relationship and access to a dementia care expert as particularly beneficial. This dichotomy highlights that perceived benefit for most of the interviewed caregivers was not captured with the formal instruments used by the program.

INTRODUCTION

There are an estimated 5.8 million people living with Alzheimer's dementia in the United States.[1] The diagnosis of dementia requires change in cognition and behaviors, that are severe enough to affect a person's ability to manage their activities of daily life.[2] Alzheimer's disease causes changes in a person's memory, insight, judgment, and ability to communicate, and is the most commonly diagnosed form of dementia.[3] In America, an estimated 18.6 billion hours of unpaid caregiving from friends and family members were spent caring for people with Alzheimer's and related dementias in 2020 which is approximated to be worth $244 billion.[1] Caregiving for people with dementia is especially demanding because the loss of function, presence of behavioral symptoms, and the extended course of the disease over several years cause continued challenges.[4]

Many family caregivers often become overwhelmed with the responsibilities of caring for a person living with dementia (PLWD) and suffer from stress and depression.[1] They often have difficulty knowing where to turn for education, guidance, and support. Appointments with the PLWD's physician are typically consumed with medication management and laboratory results, leaving little time to discuss dementia, prognosis, behavioral and psychological symptoms in dementia (BPSD), and the need for long-term planning. Community-based organizations (CBOs) can offer support and education but are often not well-integrated in the medical visit and with the healthcare system. These gaps in care led to the creation of the University of California, Los Angeles (UCLA) Alzheimer's and Dementia Care (ADC) program in which advanced practice nurse Dementia Care Specialists (DCS) who are trained on the unique challenges of the PLWD and their family members, use a co-management approach to providing dementia care. The DCS educates and guides families to better understand dementia, recognizing and managing the challenges associated with the current stage of dementia and how to prepare for future needs and crises. Through longitudinal, continuous care, the DCS is available to the PLWD and their family caregivers to provide dementia-related medical management, linkages to community resources, and health education about dementia.

While the majority of PLWD and caregiver participants in the UCLA ADC had improvement in neuropsychiatric symptoms or their caregivers had reduced strain, depression, or distress at one year,[5] 25% of dyads did not benefit based on these outcome

measures. To learn why some participants did not improve, we surveyed and interviewed caregivers of 53 participants who did not demonstrate clinical benefit. Based on the information learned from this subset of caregivers, potential program modifications and improvements can be made.

METHODS

This study used a mixed-methods design using the first 1,091 dyads followed longitudinally in the ADC program. Of those 1,091 dyads, 151 caregivers were identified as not benefitting from the ADC program based on the PLWD and caregiver clinical outcomes at 1 year. Those who did not benefit were the focus of this analysis.

Description of Program.

The UCLA ADC program was created in 2011 to provide comprehensive, coordinated dementia care for PLWD and their family caregivers.[6] To date, the program has cared for over 3,000 PLWD-caregiver dyads. The DCS meets with the dyad in person to perform an individualized needs assessment and create a dementia care plan. The ADC program is a longitudinal co-management model in which the DCS works with the referring physician to provide ongoing dementia care. In addition to providing medical care and support from within the healthcare system, the ADC program forms formal partnerships with CBOs and helps to connect dyads with local resources.

Qualitative Data Collection and Analysis.

The 151 caregivers were assigned an order through a random number process and then separated into types of caregivers (purposeful sampling) and then called in order. Approximately one-quarter of the sample was selected for semi-structured interviews, while the remaining caregivers, and those that did not want to participate in the interviews, were surveyed. Research assistants called caregivers, administered consent, and completed 12 semi-structured interviews that included both open-ended and structured responses. All telephone interviews were recorded and transcribed verbatim. The interviews were read in their entirety and, using content analysis, meaning units were identified as portions of the interview that provided answers to the research question.[7] These meaning units were coded, grouped, and larger categories or themes were created. In an effort to increase validity, this process was repeated independently by a second researcher who was familiar with the ADC program. Emerging themes and exemplary texts were discussed among the full study team and any differences in coding were settled by group consensus. Representational quotes were used to illustrate the data.

Surveys were administered to the remaining sample of caregivers by mail, telephone, or online to provide additional insight on their experience in the program, including why the program did not seem to help them and what additional services might have been more helpful.

Measures.

Two types of measures were used. The first was to identify participants who did not respond to the program. These measures included the Neuropsychiatric Inventory Questionnaire (NPI-Q),[8] a survey that assesses the caregiver's perception of the severity of 12 dementia-related psychiatric and behavioral symptoms and the level of distress experienced by the caregiver in response to these symptoms; the Modified Caregiver Strain Index (MCSI),[9] a 13-item validated tool used to assess severity of caregiver strain; the Patient Health Questionnaire-9 (PHQ-9),[10] a 9-item validated tool used to assess depressive symptoms in the caregiver using the DSM-IV criteria for major depression; and the Dementia Burden Scale-Caregiver (DBS-CG)[5] a composite of the NPI-Q Distress, MCSI, and PHQ-9 scales.

The second measures (Appendix A) were specific to this study and sought to determine why participants did not respond to the intervention and how the program could be improved. These included evaluations of specific services and referrals provided by the program, as well as identifying barriers that the caregivers believed kept them from finding the ADC helpful.

Quantitative Data Analysis.

We used the NPI-Q severity scale to define PLWD benefit (i.e., having a 1-year score of   6 or having a baseline score of > 9 and improving by at least 3 points). Three points has been previously established as the minimal clinically important difference in change in NPI-Q severity score. [11] DBS-CG benefit is scored using a possible range of 0–100. DBS-CG benefit was defined as having a 1-year score of   17.8 or having a baseline score of > 22.8 and improving by at least 5 points, the minimal clinically important difference.[5] Defining benefit in this manner identified those who maintained low symptoms and had improved symptoms from the program. Those who did not benefit based on these criteria were the focus of this analysis.

Differences in sociodemographic and baseline clinical characteristics between those who completed interviews or surveys and those who did not were compared using t-tests and chi square tests, as appropriate. All analyses were performed using R version 4.0.3. The study was approved by the California State University, Fresno and the UCLA Institutional Review Boards.

RESULTS

Of 151 participants who were identified as not clinically benefitting from the program, 40 were randomly selected to be interviewed, and 12 (30%) agreed. These included 7 interviews with daughters, 2 interviews with wives, 2 interviews with husbands, and 1 interview with a son. The remaining 111 were surveyed and 41 (36%) responded. Sociodemographic characteristics of the PLWD and their caregivers who were included in the study and those who were not sampled or did not respond are provided in Table 1. Caregivers who provided responses had slightly higher NPI-Q distress scores, but these differences were below the minimal clinically important difference for this scale.

During the interviews, most caregivers (9 of the 12 interviewed) expressed their appreciation for being in the program and were surprised to hear that they had been identified as caregivers who did not benefit from the ADC program. One husband shared "Everything that [DCS] did I found helpful... I may not have taken advantage of things...but I found her attention to detail and personalizing everything... I found so very helpful. That I did." The qualitative analysis identified seven themes around potential program improvement, including: 1) recommendations that did not match caregiver perceived care needs, 2) barriers to accessing care and utilizing resources, 3) differing care needs based on stage of dementia, 4) needing services not offered by the ADC, 5) needing more education or support, 6) behavioral recommendations that the caregiver felt did not work, and 7) poor rapport of the dementia expert with caregivers.

Recommendations did not Match Perceived Care Needs

The most commonly mentioned theme among the caregivers interviewed was the sentiment that recommendations made by the Dementia Care Specialist (DCS) did not match caregiver's perceived care needs or were deemed to be unneeded. Examples of these recommendations include: advance care planning, referrals to specialists (e.g., neurology or psychiatry), transportation assistance, and adult day care. Home safety recommendations (e.g., home modifications, Safe Return bracelet) were most frequently reported by caregivers as unnecessary. Some caregivers felt that they had already adequately addressed safety issues while some lacked insight into risks. For example, even when the PLWD had a history of wandering, some caregivers felt that neither the Safe Return nor a GPS location system was needed. One husband said, "Well I didn need it thank goodness because I was able to track my wife...every time she disappeared, I was able to track her down."

Support group referrals were the next most commonly cited unneeded recommendation. Caregivers expressed several reasons why they felt support groups did not meet their perceived needs and therefore did not attend them. Some caregivers felt that a support group would not help to address their issues with caregiver burden, others felt it was an additional burden to attend, and others were not receptive to sharing concerns in a group setting. For example, when asked to describe the reason why she felt that a support group recommendation was unneeded, one wife said:

> ...you know we are not ready...we are not ready...when the time comes, when I am no longer able to handle it, that is going to be completely different. Right now I know I am tired, I know I need my day off or something...but like I said, I am able to handle.

Barriers to Accessing and Utilizing Care and Service

Caregivers identified several perceived barriers to accessing and utilizing recommended services including difficulties with transportation, location of services, lack of respite care, challenges with computer-based resources, and services that were not in the patien s primary language. One caregiver described trouble getting to the appointment due to expensive parking and difficulty with physical transportation. Another caregiver explained that the recommendation for adult day programs was not helpful as the location wasn close enough to their home. Lack of respite care was identified as a barrier to attending support groups

and education classes. As one daughter shared, "Yeah, if they could do like home visits it would be easier because I cannot leave my mom alone and go... I couldn leave my mom alone and go."

Severe caregiver burden was another common barrier to accessing dementia care and services. Some caregivers described feeling overwhelmed with the responsibility of taking care of the PLWD, which in and of itself was a barrier. One daughter explained the difficulty she had attending a support group:

> ... When someone needs it the most, you're too overwhelmed. Like caregiving, and I was finishing up school, there was no time. And tha s why the behaviors were more challenging. Tha s when you feel you hit rock bottom and you have to just figure it out. I'm not sure...my mom, brother and I were just figuring it out on our own. You can stay at rock bottom, you know? Because how are you going to help out your loved one?

Care Needs Varied by Dementia Stage

Caregivers also articulated that care needs changed with the progression of dementia and the appropriateness of DCS recommendations in relation to the PLWD's stage of dementia was important. From one daughter's perspective, getting help earlier in the disease progression would have been more valuable:

> Again, for you to be an end-all, be-all and a go-to kind of thing, it would have been super helpful if I had known about you guys in the beginning...because it would have been like a one-stop shop instead of me flailing around. Because I had to pull a bunch of things together to make it work in Fresno. I think tha s the big difference for me, I was four years in, of an eight-year journey when I met you guys, so it was like, okay, whatever. I s always good to have a second opinion and I already had everything in place by the time I got you guys.

For others, entering the ADC program during the late stages of the PLWD's dementia wasn helpful as caregivers felt they had already learned what they needed to on their own, rendering the program unnecessary. One wife felt that she had learned what she needed over time and did not see the benefit of the ADC program:

> I wasn impressed honestly...I felt like it wasted my time honestly...like pushing, pushing, pushing...and you know...when you're taking care of somebody for so many years you don need to go to all these places honestly...you know you already learn and i s a daily basis you learn...

Needed Services Not Offered by the ADC

Some of the caregivers interviewed identified the need for different services that they felt weren offered by the ADC program. For example, a caregiver cited the need for individual counseling and more in-depth one-on-one education rather than support and education in a group setting. Some caregivers requested services that were beyond what the DCS was able to accommodate or were beyond the DCS' scope of practice. For example, a caregiver wanted the DCS to make senior living recommendations and wanted 24-hour access to their

DCS in case of emergency, instead of using the on-call geriatrics practice. One daughter wanted access to a nutritionist in the ADC program "...you know what I would like, I would like a nutritionist. A nutritionist that can tell you about a diet for the brain, like the Mediterranean diet..."

Needed More Education or Support

Another theme was the feeling that the ADC program needed to provide more education or support. For example, one daughter wanted more frequent contacts from the DCS:

> I think that the main thing that comes to mind now would be if they contact us regularly on the phone... even though they can come and visit...like regularly call the patien s family because every new change happens with them. I s not like that once a month or a few weeks or even a week be in touch for updates...if they could call them regularly...so it will be...the family won feel alone and more support and you know more you talk to them, the more education and the more support.

Poor Rapport of Dementia Expert with Family Caregivers

In one interview, a caregiver noted that she considered the DCS' approach to be too "heavy-handed."

> So you think you got everything ok, and then somebody comes in and doesn exactly like wha s going on. So making suggestions needs to be made delicately, I guess. Because if you come in and say something harsh, here I am doing the best I can, I'm working full time, I'm trying to care for my mom, and someone doesn like...the suggestions need to be gently presented. Because this journey is horrible as it is. So being gentle is the best thing.

Another caregiver felt like the counseling she received at one of the community-based organizations would have been more helpful if it was with a licensed counselor instead of a counselor-in-training, specifically citing that the counselor did not seem prepared.

Behavioral Recommendations that the Caregiver Felt Did Not Work

Non-pharmacological behavioral modifications are often taught to family caregivers as a way to manage the PLWD's behaviors. Examples include maintaining a daily schedule, improving communication skills, and learning to redirect or reorient the PLWD. Often these strategies are used in conjunction with medication to treat behaviors, but whether they are used alone or with pharmaceutical intervention they are not always effective as one daughter described:

> I do have to say they are great in theory. And in theory they make perfect sense. But come reality it is a little more challenging to implement because some of the time, say if that person is going to do that behavior, it doesn matter what you do or how you react or don react, how you respond or don respond, they will do that or continue to do that. Maybe if we were to react, maybe it would make the behavior worse. But it doesn stop the behavior in other words. In theory, if you don react the behavior will stop. Like some of them were so cookie-cutter, I'm like 'uh huh, you have no idea'.

Of 53 caregivers who did not have clinical benefit from the ADC program and responded to the interviews and surveys, 45 (85%) felt that being enrolled in the ADC was very beneficial to extremely beneficial. However, the 56% of caregivers who felt overwhelmed were less likely to perceive the program as being very or extremely beneficial (76% versus 100%, p=0.042).

Table 2 shows the services recommended by the ADC and how beneficial these were perceived to be by caregivers. The most commonly recommended services were educational resources (94%), safety recommendations (87%), and advance care planning (87%). Recommendations in all categories were perceived as beneficial by at least 75% of respondents except private respite services (73%) and support groups (68%). Support groups were less frequently perceived as beneficial compared to counseling (90%), and respite services were less frequently perceived as beneficial compared to adult day care (80%).

DISCUSSION

This mixed methods study attempted to identify reasons why some PLWD and their caregivers did not benefit from a comprehensive, nurse practitioner-led dementia care program. Of note, this lack of benefit was defined by scores on validated measures of PLWD behavioral symptoms and caregiver strain, distress, and depression. Despite lack of benefit on these measures, 85% of the caregivers interviewed or surveyed felt that their participation in the ADC program was beneficial suggesting there are benefits to dementia care management that are not well captured by some validated measures of caregiver strain, depression, and distress due to behavioral symptoms.

In qualitative analyses, we identified seven themes of potential reasons for lack of clinical benefit among dyads that may inform the ADC and other dementia care programs. Some recommendations, such as those for safety, support groups, and adult day care, did not seem to fit the caregivers' perceived current needs or were deemed inappropriate for the PLWD's stage of dementia. For example, some caregivers had already tried behavioral interventions and felt that these no longer were effective. Another theme was barriers that interfered with the caregivers' ability to access beneficial services including location, costs, lack of respite care, and technology. Other themes related to needing more intensive support or counseling services than could be provided by the program. Finally, some caregivers never established good rapport with the dementia care team. Many issues identified in this study are addressable in theory but harder in practice due to care delivery constraints created by our current Fee-for-service payment model. For example, some caregivers wanted more individualized or additional DCS contact which would only be possible with changes to provider reimbursement to allow for services such as telephone and telemedicine visits, time to research community caregiver and PLWD services, and vouchers or other payments to CBOs for private pay services (e.g. adult day care, counseling, education).

We also found that caregivers may not respond to the program because the burden of caregiving had overwhelmed them, consistent with estimates that 59% of family caregivers that care for a PLWD describe their emotional stress of caregiving as high to very high.[1] If a caregiver is too overwhelmed to obtain help in the community or to learn more about the

PLWD's disease and its progression, they may not be able to take advantage of program services or may not see the benefit of a dementia care program.

In addition to perceiving the program as being beneficial, the vast majority of caregivers perceived individual recommendations as beneficial. However, individual counseling and adult day programs were more commonly perceived as more beneficial than support groups and private respite care, respectively. More individualized and intensive services may better meet caregiver needs for personal support and time away from caregiving.

Changes made to the program over the last 7 years have addressed some of the feedback provided by the caregivers. For example, in the second year of the program, vouchers were provided on a limited basis for participants to use for services such as individual counseling, private case management, and adult daycare that are typically out-of-pocket expenses. These particular services were identified as important for certain dyads who previously could not access these due to financial constraints. Support groups focused on the needs of persons with early onset Alzheimer's disease and other rare dementia types were formed. A one-day caregiver educational "bootcamp" with provision of respite care was developed. Future research is needed to better gauge the current dyad experience in the ADC program and determine if additional modifications are needed.

The limitations of this study are important to note. This study sought caregivers of dyads that did not benefit based on objective measures, which could only be determined after they returned for their one-year annual visit. Thus, we were unable to capture a segment of dyads who did not agree to come back for an annual visit (49%)[5]. Some of these dyads may not have benefited from the program and may have been able to provide additional insights. The response rate of caregivers to our survey was 36%. However, the purpose of the study was to generate ideas to improve dementia care programs rather than obtain accurate quantitative data for population estimates. In addition, the interviews and surveys were conducted after some PLWD had left the program due to death or other reasons and relied on the caregiver being able to remember their experience. The study was limited to one program that was implemented at one site. Hence, the findings may not apply to other sites or other dementia care programs.

The UCLA ADC program was created in response to the need to improve dementia care for PLWD and their family caregivers. Although three-quarters of dyads demonstrated clinical benefit at 1 year, one-quarter did not. The finding that the vast majority of non-responders rated the program as beneficial suggest that other unmeasured benefits may have been achieved by receiving dementia care management. Furthermore, individual recommendations and services were rated highly. We also noted that caregivers who felt overwhelmed were less likely to perceive benefit from the program suggesting that this group may have greater unmet needs or need novel approaches to care and services. Insights gained from this study may guide dementia care programs to refine the services provided and researchers to develop new measures to quantify benefit.

Funding

Appendix

ADC ID #:

1. Please indicate below:
How would you rate your experience with the Alzheimer's and Dementia Care Program?

Not at all beneficial	Slightly beneficial	Moderately beneficial	Very beneficial	Extremely beneficial
☐	☐	☐	☐	☐

While involved in the program, your Dementia Care Manager may have provided different types of help. We would like to ask you about each of these specifically. For each type of help, please tell us if it was provided to you or not and, if provided, how helpful it was.

2. Educational resources about dementia and what to expect in the future		
☐ Provided	☐ Not Provided	☐ Not Needed

a. If PROVIDED: Were they helpful?	
☐ Helpful	☐ Not Helpful

b. If NOT HELPFUL: Please indicate why the educational resources about dementia were not helpful: (check all that apply)

☐	Resources did not match my needs or the person with dementia's needs
☐	Resources were low quality
☐	Resources were not convenient to use
☐	I was not interested in using the resources
☐	I did not have enough information about the resources to use them
☐	Other: _____

3. Recommendations or resources to address behavioral symptoms of dementia, such as agitation, delusions, sundowning, repetitive questions, or other behaviors		
☐ Recommended	☐ Not Recommended	☐ Not Needed

a. If RECOMMENDED: Were these recommendations/resources helpful to you?	
☐ Helpful	☐ Not Helpful

b. If NOT HELPFUL: Please indicate why the recommendations or resources were not helpful: (check all that apply)

☐	Behavioral recommendations/resources did not match my needs/person with dementia's needs
☐	Behavioral recommendations/resources were low quality
☐	Behavioral recommendations/resources were not convenient to use
☐	I was not interested in using the behavioral recommendations/resources
☐	I did not have enough information about the behavioral recommendations/resources to use them
☐	Other: _____

1

4. Help coordinating the patient's medical care (i.e. doctors' appointments, medications, hospitalizations)		
☐ Provided	☐ Not Provided	☐ Not Needed
a. If PROVIDED: Was this helpful to you?		
☐ Helpful		☐ Not Helpful
b. If NOT HELPFUL: Please indicate why this was not helpful: (check all that apply)		
☐	Help coordinating medical care did not match my needs or the person with dementia's needs	
☐	Help coordinating medical care was low quality	
☐	Help coordinating medical care was not convenient to use	
☐	I was not interested in help coordinating medical care	
☐	I did not have enough information about help coordinating medical care	
☐	Other: _____	

5. Referrals to specialists, such as a neurologist or psychiatrist		
☐ Referred	☐ Not Referred	☐ Not Needed
a. If REFERRED: Were these referrals helpful to you?		
☐ Helpful		☐ Not Helpful
b. If NOT HELPFUL: Please indicate why the referrals were not helpful: (check all that apply)		
☐	Referral did not match my needs or the person with dementia's needs	
☐	Referral was low quality	
☐	Referral was not convenient to use	
☐	I was not interested in using the referral	
☐	I did not have enough information about the referral to use it	
☐	Other: _____	

6. Referral to adult day care		
☐ Referred	☐ Not Referred	☐ Not Needed
a. If REFERRED: Was this referral helpful to you?		
☐ Helpful		☐ Not Helpful
b. If NOT HELPFUL: Please indicate why the referral was not helpful: (check all that apply)		
☐	Referral did not match my needs or the person with dementia's needs	
☐	Referral was low quality	
☐	Referral was not convenient to use	
☐	I was not interested in using the referral	
☐	I did not have enough information about the referral to use it	

2

☐	Other: _____

7. Referrals to counseling

☐ Referred	☐ Not Referred	☐ Not Needed

a. If REFERRED: Were these referrals helpful to you?

☐ Helpful	☐ Not Helpful

b. IF NOT HELPFUL: Please indicate why the referrals were not helpful: (check all that apply)

☐	Counseling referral did not match my needs or the person with dementia's needs
☐	Counseling was low quality
☐	Counseling was not convenient to use
☐	I was not interested in using counseling
☐	I did not have enough information about the counseling referral to use it
☐	Other: _____

8. Safety recommendations, such as recommendations to reduce fall risk or to reduce home hazards

☐ Recommended	☐ Not Recommended	☐ Not Needed

a. If RECOMMENDED: Were these recommendations helpful to you?

☐ Helpful	☐ Not Helpful

b. If NOT HELPFUL: Please indicate why the recommendations were not helpful: (check all that apply)

☐	Safety recommendations did not match my needs/person with dementia's needs
☐	Safety recommendations were low quality
☐	Safety recommendations were not convenient to use
☐	I was not interested in using the safety recommendations
☐	I did not have enough information about the safety recommendations to use them
☐	Other: _____

9. Resources for short-term breaks for caregivers or respite (i.e. in-home care or private pay caregivers)

☐ Provided	☐ Not Provided	☐ Not Needed

a. If PROVIDED: Were these helpful?

☐ Helpful	☐ Not Helpful

b. If NOT HELPFUL: Please indicate why the resource was not helpful: (check all that apply)

☐	Resource recommended did not match my needs or the person with dementia's needs
☐	Resource was low quality
☐	Resource was not convenient to use
☐	I was not interested in using the resource
☐	I did not have enough information about the resource to use it

3

□	Other: _____

10. Advance Care Planning, such as discussing end-of-life care preferences or establishing a power of attorney or completing a POLST form or hospice or palliative care		
□ Provided	□ Not Provided	□ Not Needed
a. If PROVIDED: Was it helpful?		
□ Helpful		□ Not Helpful
b. If NOT HELPFUL: Please indicate why the resource was not helpful: (check all that apply)		

□	I had already completed advance care planning
□	Advance care planning discussion/resources did not match my needs or the person with dementia's needs
□	Advance care planning discussion/resources were low quality
□	Advance care planning discussion/resources were not convenient to use
□	I was not interested in having an advance care planning discussion or using the resources provided
□	I did not have enough information about the advance care planning resources to use them
□	Other: _____

11. Support Groups		
□ Referred	□ Not Referred	□ Not Needed
a. If REFERRED: Was the referral helpful to you?		
□ Helpful		□ Not Helpful
b. If NOT HELPFUL: Please indicate why the referral was not helpful: (check all that apply)		

□	I was already attending support groups
□	Support groups did not match my needs or the person with dementia's needs
□	Support group referral was low quality
□	Support group referral was not convenient to use
□	I was not interested in attending a support group
□	I did not have enough information about the support group to use it
□	Other: _____

4

12. Transportation Services		
☐ Referred	☐ Not Referred	☐ Not Needed
a. If REFERRED: Was the referral helpful to you?		
☐ Helpful		☐ Not Helpful
b. If NOT HELPFUL: Please indicate why the referral was not helpful: (check all that apply)		
☐	Transportation service recommended did not match my needs or the person with dementia's needs	
☐	Transportation service was low quality	
☐	Transportation service was not convenient to use	
☐	I was not interested in using transportation service	
☐	I did not have enough information about the transportation service to use it	
☐	Other: _____	

13. Legal Resources		
☐ Referred	☐ Not Referred	☐ Not Needed
a. If REFERRED: Was the referral helpful to you?		
☐ Helpful		☐ Not Helpful
b. If NOT HELPFUL: Please indicate why the referral was not helpful: (check all that apply)		
☐	The referral did not match my needs or the person with dementia's needs	
☐	The referral was low quality	
☐	The referral was not convenient to use	
☐	I was not interested in using legal services	
☐	I did not have enough information about the referral to use it	
☐	Other: _____	

We also want to know if you experienced any barriers in attending program appointments, communicating with your Dementia Care Manager, or in using resources or services recommended by your Dementia Care Manager.

For each of the following, please indicate if it was a barrier for you.

14. Was getting the person with dementia to appointments or to community organizations a barrier for you?				
☐ Yes			☐ No	
a. If YES: How difficult was it to get the person with dementia to appointments or community organizations?				
☐ Not Difficult at	☐ Slightly Difficult	☐ Moderately	☐ Very Difficult	☐ Extremely

5

All		Difficult		Difficult

15. Was reaching someone from the program a barrier for you?

☐ Yes	☐ No

a. **If YES: How difficult was it to reach someone from the program?**

☐ Not Difficult at All	☐ Slightly Difficult	☐ Moderately Difficult	☐ Very Difficult	☐ Extremely Difficult

b. **If any difficulty, please explain:**

16. Was finding another person to stay with the person with dementia so you could attend caregiver support groups or classes a barrier for you?

☐ Yes	☐ No

a. **If YES: How difficult was finding another person to stay with the person with dementia?**

☐ Not Difficult at All	☐ Slightly Difficult	☐ Moderately Difficult	☐ Very Difficult	☐ Extremely Difficult

17. Was lack of time to use resources a barrier for you?

☐ Yes	☐ No

a. **If YES: How difficult was it to find time to use resources recommended by your Dementia Care Manager?**

☐ Not Difficult at All	☐ Slightly Difficult	☐ Moderately Difficult	☐ Very Difficult	☐ Extremely Difficult

18. Was feeling overwhelmed a barrier for you?

☐ Yes	☐ No

a. **If YES: How difficult was it to manage feelings that you were overwhelmed?**

☐ Not Difficult at All	☐ Slightly Difficult	☐ Moderately Difficult	☐ Very Difficult	☐ Extremely Difficult

19. Was the cost of services (e.g., cost of adult day care or case management) a barrier for you?

☐ Yes	☐ No

a. **If YES: How difficult was it to use services due to cost?**

☐ Not Difficult at All	☐ Slightly Difficult	☐ Moderately Difficult	☐ Very Difficult	☐ Extremely Difficult

6

20. How likely are (were) you to contact your UCLA Dementia Care Manager when faced with a dementia related concern (e.g. change in behavior, ER visit, hospitalization, or caregiver stress)?

Not likely to contact	Slightly likely to contact	Moderately likely to contact	Very likely to contact	Extremely likely to contact
☐	☐	☐	☐	☐

21. Are there barriers that you experienced that were not mentioned?

☐ Yes; please specify: _____

_____

_____

☐ No

Please indicate whether you agree or disagree with each of the following statements about the patient's care in the UCLA Alzheimer's and Dementia Care Program and your experiences with caregiving. If the patient with dementia has died, please reflect back on your experiences when the person was enrolled in the program.

22. I know where to turn to get answers to questions about problems like the patient's memory loss, wandering or behavior problems.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
☐	☐	☐	☐	☐

23. I feel confident that I can handle problems like the patient's memory loss, wandering or behavior problems.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
☐	☐	☐	☐	☐

24. I know how to get community services that will help me provide care.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
☐	☐	☐	☐	☐

25. I feel confident that I can deal with the frustrations of caregiving.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
☐	☐	☐	☐	☐

26. I have a healthcare professional who helps me work though dementia care problems.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
☐	☐	☐	☐	☐

7

Is there any other information about your experience with the UCLA Alzheimer's and Dementia Care program that you think we should know?

8

References

1. 2020 Alzheimer's disease facts and figures. Alzheimer's Dement. Published online 2020. 10.1002/alz.12068

2. National Institute on Aging. What is Dementia? Symptoms, Types, and Diagnosis. Basics of Alzheimer's Disease and Dementia. Published 2017. https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis

3. American Psychiatric Association. Published 2017. Accessed January 1, 2019. www.psychiatry.org/patients-families/alzheimers/what-is-alzheimers-disease

4. Kasper J, Freedman V, Spillman B, Wolff J. The Disproportionate Impact Of Dementia On Family And Unpaid Caregiving To Older Adults. Health Aff. 2015;34(10):1642–1649B. 10.1377/hlthaff.2015.0536

5. Reuben DB, Tan ZS, Wenger NS, Romero T, Keeler E, Jennings LA. *Patient and Caregiver Benefit from a Comprehensive Dementia Care Program.*; 2019.

6. Reuben DB, Evertson LC, Wenger NS, et al. The University of California at Los Angeles Alzheimer's and Dementia Care Program for Comprehensive, Coordinated, Patient-Centered Care:

Preliminary Data. J Am Geriatr Soc. 2013;61(12):2214–2218. 10.1111/jgs.12562 [PubMed: 24329821]

7. Bengtsson M. How to plan and perform a qualitative study using content analysis. Nursingplus Open. 2016;2. 10.1016/j.npls.2016.01.001

8. Kaufer DI, Cummings JL, Ketchel P, et al. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. J Neuropsychiatry Clin Neurosci. 2000;12(2):233–239. [PubMed: 11001602]

9. Thornton M, Travis SS. Analysis of the Reliability of the Modified Caregiver Strain Index. Journals Gerontol Ser B Psychol Sci Soc Sci. 2003;58(2):S127–S132.

10. Kroenke K, Spitzer RL, Williams JBW. Validity of a brief depression severity measure. J Gen Intern Med. 2001;16(9):606–613. [PubMed: 11556941]

11. Mao H, Kuo C, Huang W, Cummings JL, Hwang T. Values of the minimal clinically important difference for the Neuropsychiatric Inventory Questionnaire in individuals with dementia. J Am Geriatr Soc. 2015;63(7):1448–1452. [PubMed: 26046666]

Highlights

- Caregivers perceive benefit from dementia care despite being identified as not benefiting using formal instruments.

- Identified barriers to helpful dementia care may not be easily addressed due to care delivery constraints created by our current Fee-for-service payment model.

- Caregivers who felt overwhelmed were less likely to perceive benefit.

Table 1:

Caregiver characteristics stratified by survey completion, N=151.

Variable	Did not complete surveys n = 98 (65%)	Completed interviews/surveys n = 53 (35%)	p-value
Female	71 (72.4%)	41 (77.4%)	0.563
Relationship to PLWD			0.873
Female Spouse	23 (23.5%)	10 (18.9%)	
Male Spouse	11 (11.2%)	8 (15.1%)	
Female Child	37 (37.8%)	24 (45.3%)	
Male Child	11 (11.2%)	4 (7.5%)	
Friend or other family member	14 (14.3%)	6 (11.3%)	
Paid caregiver	2 (2%)	1 (1.9%)	
Race			0.647
White	58 (81.7%)	29 (74.4%)	
African American	8 (11.3%)	5 (12.8%)	
Asian	3 (4.2%)	4 (10.3%)	
Hispanic	1 (1.4%)	1 (2.6%)	
Other	1 (1.4%)	0 (0%)	
DBS-CG	24.5 (16.8–32.2)	30.1 (21–35.5)	0.211
MCSI (n= 142)	9 (6–14)	10.5 (7–14)	0.456
NPI-Q-Distress Score (n= 148)	10 (5–14)	12 (7–20)	0.041
Caregiver PHQ-9 (n= 148)	3.5 (1.8–7)	4 (2–8)	0.642

DBS-CG = Caregiver Dementia Burden Score; MCSI = Modified Caregiver Strain Index; NPI-Q = Neuropsychiatric Inventory Questionnaire; PHQ-9 = Patient Health Questionnaire.

Table 2:

Caregiver Receipt and Perception of Care Recommendations (N=53).

Variable	N (%) Receiving recommendation	N (%) perceiving recommendation as beneficial
Educational Resources	50 (94%)	47 (94%)
Behavioral management (non-pharmacological)	18 (34%)	18(100%)
Coordinating medical care	16 (30%)	15 (94%)
Referral to specialist	13 (25%)	12 (92%)
Adult day care	30 (57%)	24 (80%)
Counseling	29 (55%)	26 (90%)
Safety recommendation	46 (87%)	39 (85%)
Respite care / stay	37 (70%)	27 (73%)
Advance care planning	46 (87%)	43 (93%)
Support groups	40 (75%)	27 (68%)
Transportation services	8 (15%)	8 (100%)
Legal resources	2 (4%)	2 (100%)