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Featured Article

Caregiver outcomes of a dementia care program

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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 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.

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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.

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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

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.

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’t 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 patient’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’t 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’t 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 that’s why the behaviors were more challenging. That’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 that’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. It’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’t 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’t 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’t need to go to all these places honestly. . .you know you already learn and it’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’t 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't come and visit...like regularly call the patient's family because every new change happens with them. It'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't 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't exactly like what'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't 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't matter what you do or how you react or don't react, how you respond or don't 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't stop the behavior in other words. In theory, if you don't 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
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%)

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.

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Appendices

[Appendix A](#)

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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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		
<input type="checkbox"/> Provided	<input type="checkbox"/> Not Provided	<input type="checkbox"/> Not Needed
a. If PROVIDED: Were they helpful?		
<input type="checkbox"/> Helpful	<input type="checkbox"/> Not Helpful	
b. If NOT HELPFUL: Please indicate why the educational resources about dementia were not helpful: (check all that apply)		
<input type="checkbox"/>	Resources did not match my needs or the person with dementia’s needs	
<input type="checkbox"/>	Resources were low quality	
<input type="checkbox"/>	Resources were not convenient to use	
<input type="checkbox"/>	I was not interested in using the resources	
<input type="checkbox"/>	I did not have enough information about the resources to use them	
<input type="checkbox"/>	Other: _____	

3. Recommendations or resources to address behavioral symptoms of dementia, such as agitation, delusions, sundowning, repetitive questions, or other behaviors		
<input type="checkbox"/> Recommended	<input type="checkbox"/> Not Recommended	<input type="checkbox"/> Not Needed
a. If RECOMMENDED: Were these recommendations/resources helpful to you?		
<input type="checkbox"/> Helpful	<input type="checkbox"/> Not Helpful	
b. If NOT HELPFUL: Please indicate why the recommendations or resources were not helpful: (check all that apply)		
<input type="checkbox"/>	Behavioral recommendations/resources did not match my needs/person with dementia’s needs	
<input type="checkbox"/>	Behavioral recommendations/resources were low quality	
<input type="checkbox"/>	Behavioral recommendations/resources were not convenient to use	
<input type="checkbox"/>	I was not interested in using the behavioral recommendations/resources	
<input type="checkbox"/>	I did not have enough information about the behavioral recommendations/resources to use them	
<input type="checkbox"/>	Other: _____	

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

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

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

7. Referrals to counseling		
<input type="checkbox"/> Referred	<input type="checkbox"/> Not Referred	<input type="checkbox"/> Not Needed
a. If REFERRED: Were these referrals helpful to you?		
<input type="checkbox"/> Helpful	<input type="checkbox"/> Not Helpful	
b. If NOT HELPFUL: Please indicate why the referrals were not helpful: (check all that apply)		
<input type="checkbox"/>	Counseling referral did not match my needs or the person with dementia's needs	
<input type="checkbox"/>	Counseling was low quality	
<input type="checkbox"/>	Counseling was not convenient to use	
<input type="checkbox"/>	I was not interested in using counseling	
<input type="checkbox"/>	I did not have enough information about the counseling referral to use it	
<input type="checkbox"/>	Other: _____	

8. Safety recommendations, such as recommendations to reduce fall risk or to reduce home hazards		
<input type="checkbox"/> Recommended	<input type="checkbox"/> Not Recommended	<input type="checkbox"/> Not Needed
a. If RECOMMENDED: Were these recommendations helpful to you?		
<input type="checkbox"/> Helpful	<input type="checkbox"/> Not Helpful	
b. If NOT HELPFUL: Please indicate why the recommendations were not helpful: (check all that apply)		
<input type="checkbox"/>	Safety recommendations did not match my needs/person with dementia's needs	
<input type="checkbox"/>	Safety recommendations were low quality	
<input type="checkbox"/>	Safety recommendations were not convenient to use	
<input type="checkbox"/>	I was not interested in using the safety recommendations	
<input type="checkbox"/>	I did not have enough information about the safety recommendations to use them	
<input type="checkbox"/>	Other: _____	

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

a. If PROVIDED: Were these helpful?	
<input type="checkbox"/> Helpful	<input type="checkbox"/> Not Helpful
b. If NOT HELPFUL: Please indicate why the resource was not helpful: (check all that apply)	
<input type="checkbox"/>	Resource recommended did not match my needs or the person with dementia's needs
<input type="checkbox"/>	Resource was low quality
<input type="checkbox"/>	Resource was not convenient to use
<input type="checkbox"/>	I was not interested in using the resource
<input type="checkbox"/>	I did not have enough information about the resource to use it
<input type="checkbox"/>	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		
<input type="checkbox"/> Provided	<input type="checkbox"/> Not Provided	<input type="checkbox"/> Not Needed
a. If PROVIDED: Was it helpful?		
<input type="checkbox"/> Helpful	<input type="checkbox"/> Not Helpful	
b. If NOT HELPFUL: Please indicate why the resource was not helpful: (check all that apply)		
<input type="checkbox"/>	I had already completed advance care planning	
<input type="checkbox"/>	Advance care planning discussion/resources did not match my needs or the person with dementia's needs	
<input type="checkbox"/>	Advance care planning discussion/resources were low quality	
<input type="checkbox"/>	Advance care planning discussion/resources were not convenient to use	
<input type="checkbox"/>	I was not interested in having an advance care planning discussion or using the resources provided	
<input type="checkbox"/>	I did not have enough information about the advance care planning resources to use them	
<input type="checkbox"/>	Other: _____	

11. Support Groups		
<input type="checkbox"/> Referred	<input type="checkbox"/> Not Referred	<input type="checkbox"/> Not Needed
a. If REFERRED: Was the referral helpful to you?		
<input type="checkbox"/> Helpful	<input type="checkbox"/> Not Helpful	
b. If NOT HELPFUL: Please indicate why the referral was not helpful: (check all that apply)		
<input type="checkbox"/>	I was already attending support groups	
<input type="checkbox"/>	Support groups did not match my needs or the person with dementia's needs	
<input type="checkbox"/>	Support group referral was low quality	
<input type="checkbox"/>	Support group referral was not convenient to use	
<input type="checkbox"/>	I was not interested in attending a support group	
<input type="checkbox"/>	I did not have enough information about the support group to use it	
<input type="checkbox"/>	Other: _____	

12. Transportation Services		
<input type="checkbox"/> Referred	<input type="checkbox"/> Not Referred	<input type="checkbox"/> Not Needed
a. If REFERRED: Was the referral helpful to you?		
<input type="checkbox"/> Helpful	<input type="checkbox"/> Not Helpful	

<input type="checkbox"/>	Transportation service recommended did not match my needs or the person with dementia's needs
<input type="checkbox"/>	Transportation service was low quality
<input type="checkbox"/>	Transportation service was not convenient to use
<input type="checkbox"/>	I was not interested in using transportation service
<input type="checkbox"/>	I did not have enough information about the transportation service to use it
<input type="checkbox"/>	Other: _____

13. Legal Resources		
<input type="checkbox"/> Referred	<input type="checkbox"/> Not Referred	<input type="checkbox"/> Not Needed
a. If REFERRED: Was the referral helpful to you?		
<input type="checkbox"/> Helpful	<input type="checkbox"/> Not Helpful	
b. If NOT HELPFUL: Please indicate why the referral was not helpful: (check all that apply)		
<input type="checkbox"/>	The referral did not match my needs or the person with dementia's needs	
<input type="checkbox"/>	The referral was low quality	
<input type="checkbox"/>	The referral was not convenient to use	
<input type="checkbox"/>	I was not interested in using legal services	
<input type="checkbox"/>	I did not have enough information about the referral to use it	
<input type="checkbox"/>	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?				
<input type="checkbox"/> Yes		<input type="checkbox"/> No		
a. If YES: How difficult was it to get the person with dementia to appointments or community organizations?				
<input type="checkbox"/> Not Difficult at All	<input type="checkbox"/> Slightly Difficult	<input type="checkbox"/> Moderately Difficult	<input type="checkbox"/> Very Difficult	<input type="checkbox"/> Extremely Difficult
15. Was reaching someone from the program a barrier for you?				
<input type="checkbox"/> Yes		<input type="checkbox"/> No		
a. If YES: How difficult was it to reach someone from the program?				
<input type="checkbox"/> Not Difficult at All	<input type="checkbox"/> Slightly Difficult	<input type="checkbox"/> Moderately Difficult	<input type="checkbox"/> Very Difficult	<input type="checkbox"/> 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?				
<input type="checkbox"/> Yes		<input type="checkbox"/> No		
a. If YES: How difficult was finding another person to stay with the person with dementia?				
<input type="checkbox"/> Not Difficult at All	<input type="checkbox"/> Slightly Difficult	<input type="checkbox"/> Moderately Difficult	<input type="checkbox"/> Very Difficult	<input type="checkbox"/> Extremely Difficult

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

a. If YES: How difficult was it to find time to use resources recommended by your Dementia Care Manager?				
<input type="checkbox"/> Not Difficult at All	<input type="checkbox"/> Slightly Difficult	<input type="checkbox"/> Moderately Difficult	<input type="checkbox"/> Very Difficult	<input type="checkbox"/> Extremely Difficult

18. Was feeling overwhelmed a barrier for you?				
<input type="checkbox"/> Yes	<input type="checkbox"/> No			
a. If YES: How difficult was it to manage feelings that you were overwhelmed?				
<input type="checkbox"/> Not Difficult at All	<input type="checkbox"/> Slightly Difficult	<input type="checkbox"/> Moderately Difficult	<input type="checkbox"/> Very Difficult	<input type="checkbox"/> Extremely Difficult

19. Was the cost of services (e.g., cost of adult day care or case management) a barrier for you?				
<input type="checkbox"/> Yes	<input type="checkbox"/> No			
a. If YES: How difficult was it to use services due to cost?				
<input type="checkbox"/> Not Difficult at All	<input type="checkbox"/> Slightly Difficult	<input type="checkbox"/> Moderately Difficult	<input type="checkbox"/> Very Difficult	<input type="checkbox"/> Extremely Difficult

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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24. I know how to get community services that will help me provide care.				
Strongly agree	Agree	Neutral	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

25. I feel confident that I can deal with the frustrations of caregiving.				
Strongly agree	Agree	Neutral	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26. I have a healthcare professional who helps me work through dementia care problems.				
Strongly agree	Agree	Neutral	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

Theme	Subcategories	Selected Quotes	
Recommendations that did not match perceived care needs	Safety Recommendations	<p>“... We didn't do the ID thing just because generally my mom is never left alone so it's not a caregiver it's always a family member.” (daughter)</p> <p>“My mother doesn't wander...she can't even get out of the house so she can't go anywhere. That's [Safe Return bracelet] not something we would implement.” (daughter)</p>	
	Support Groups	<p>“I didn't go to any and my caretaker, she was also just pretty good at you know managing things ...I think no one felt overburdened at any time... I'm sure for other people they'd be great though so I'd keep them in the program.” (daughter)</p> <p>“The whole advance directive is very important, but I had done all of that while I was still in Fresno.” (daughter)</p>	
	Advance Care Planning	<p>“I thought we already had that in place already but I could be wrong...I'm pretty sure we had put that in place...and I probably told her that we had one in place already...” (daughter)</p>	
	Specialist Recommendations	<p>“There was no reason for my mother to go to a psychiatrist...There was no reason.” (daughter)</p>	
	Transportation	<p>“I don't think we really took advantage of transportation services.” (daughter)</p> <p>“It [transportation recommendation] wasn't [helpful] because we engaged the caregiver...and she drives us all over when we have to go.” (husband)</p>	
	Adult Day Care	<p>“No not really [valuable] because I had good care 24/7 at home and it was not really a thing where I would take my mom out...she just didn't want to go out.” (daughter)</p> <p>“Not really [helpful] because...the daycares I have to pay for...you know...and we are not in the position...” (wife)</p>	
	Too frequent visits	<p>“Well I only needed her once that's honestly...I only need her once and I think that was in June the first time...before that they pushing me to go and I said no I already went three times and he don't need to go...and I said I'm not going I only go one time a year.” (wife)</p>	
	Support groups weren't helpful	<p>“Honestly I don't know what the goal was. I didn't get anything out of it. And I think they may have recommended a couple of groups but yeah it is really, really difficult mentally and I didn't have time for a support group... I really don't know what they could have done to improve upon it because I think it's so different for every person. And if in fact they are going to do something, you need to make it a one-day class and speed through all of it.” (daughter)</p>	
	Barriers to accessing and utilizing care and services	Parking	<p>“...there was that really horrible thing when I first went to what's the right word, I don't know, assessed and the parking is like \$12 and I'm like oh my god and I actually wrote to her and said wow that was expensive...” (daughter)</p>
		Lack of respite care	<p>“Yeah if they could do like home visits it would be easier because I cannot leave my mom alone and go... I couldn't leave my mom alone and go.” (daughter)</p>
Location		<p>“...I went to a support group at the medical center it was run by Patti Davis, Ronald Reagan's daughter I think and that was very helpful for a long time and then she moved it to Santa Monica at 5:00...it is kind of like ugh...going up to UCLA is one thing...but then getting in the car and driving all the way to Santa Monica...I stopped going to the support group.” (daughter)</p>	
Feeling overwhelmed		<p>“... You know when you go in of course they do explain like the Alzheimer's and everything but it's new, you never had to deal with it before...so it's kind of like...you know when they say, oh do you have any questions, it's kind of like no not really because I don't know honestly what question to ask...” (daughter)</p> <p>“Like I said, they may have and it could have gone in one ear and out the other at the time I was so overwhelmed and I didn't really understand why I was there. Yea I don't have the time. But I tried.” (daughter)</p>	
Technology		<p>“...you know the only thing I had trouble with was that at one point I was going to try to make one of the Alzheimer's caregiver meetings at UCLA...and yeah, I wasn't able to access the correct page...yeah I never quite made it there. I don't know whether it was the links that weren't working for me or if I was hitting something wrong, but yeah.” (daughter)</p>	
Language		<p>“...well my father, he's the Alzheimer's patient, he only speaks Greek so I know and of course having Alzheimer's, right? You can imagine it's already a challenge to communicate and then to have to communicate through me or for me to try and translate so that was certainly a challenge...not being able to participate in research studies that were of course highly recommended but he missed out on those because of the language barrier.” (daughter)</p>	
Care needs varied by dementia stage		Late stage dementia	<p>“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 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 that'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. It's always good to have a second opinion and I already had everything in place by the time I got you guys.” (daughter)</p> <p>“I wasn't 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't need to go to all these places honestly...you know you already learn and it's a daily basis you learn...” (Wife)</p>
		Needed services not offered by the ADC	<p>“Maybe a one to one in that situation that way you don't feel so vulnerable. Like one time one to one with somebody that might be able to help you, but you are not in a group setting so you don't feel uncomfortable or to vulnerable, but there's somebody to help guide you.” (daughter)</p> <p>“...if you guys had a list of board and cares versus big fancy...” (daughter)</p>
Needed more education or support	Long-term care options	<p>“Whatever I found out about the disease I found out on the Internet not by any MD or neurologist. No information about the disease...he was early onset and I know that's a special case because most people don't get early onset .so yeah, providing more information to understand, a general understanding of the disease.” (daughter)</p>	
	Education	<p>“So, I think...having someone there or if you don't like what somebody else tells you and you want a 2nd opinion, I think it's just really important...because it is like a security blanket. If you don't like what the caregivers are doing or what the MD is recommending you could go 'hey [DCS], can you help with this? Can I talk this over with you? Can you be my sounding board? With dementia, that's what you often need a sounding board. And for me personally, [the DCS was] not really...” (daughter)</p>	

(continued)

(Continued)

Theme	Subcategories	Selected Quotes
Behavioral recommendations that the caregiver felt did not work	Cookie cutter recommendations	"So, they do make sense naturally, but that would make sense for anyone. Like a child, if you were to yell back at a child...that would not help soothe them. So that's common sense, almost. (daughter)
	Recommendations did not work for them	"Not particularly [helpful] because the people who were taking care of my mom...again it's all about the situation...it might not have been helpful for me, but again that's because of my situation." (daughter)
Dementia care expert had poor rapport with caregivers	Made family feel guilty	"...we also saw a psych doctor, and he was actually the worst. When we were explaining, it was almost like making the family feel guilty, 'well if you do that, he'll be perfect' no, we do that you don't understand there is no rationality and the behavior doesn't change." (daughter)
	Inexperienced counselor	"Some of the questions that were brought up during the session... She would have to write them down and get back to us at like the next session... And if I hadn't taken notes sometimes she would forget... She had gotten the answer but I guess didn't look into her notes or something. So yeah that was the only negative about it... Was since I think she was in training him maybe not as knowledgeable as she could have been." (daughter)
	Heavy handed recommendations	"...sometimes people come in to a situation and are heavy handed with their suggestions...it only happened once..." (daughter)

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