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Caregiver Outcomes of a Dementia Care Program

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ABSTRACT

CAREGIVER OUTCOMES OF A DEMENTIA CARE PROGRAM

The University of California, Los Angeles Alzheimer's and Dementia Care (ADC) program enrolls people with dementia (PWD) 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, the PWDs' behavioral and depressive symptoms improved. In addition, at one-year, caregiver depression, distress related to behavioral symptoms, and caregiver strain also improved. Not all dyads enrolled in the ADC program appear to experience benefit. Although strain and distress remained stable or decreased for the majority of caregivers, a portion reported an increase in both. Semi-structured interviewed were completed with 12 caregivers over the telephone. Based on their answers seven themes were identified. These themes included: caregiver perception of being provided recommendations that did not match perceived care needs, existence of 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, received behavioral recommendations that the caregiver felt did not work, and dementia expert had poor rapport with caregivers. Despite having been identified as having had no clinical benefit from participating in the program, most caregivers did feel that the program was beneficial. This dichotomy highlights that perceived benefit for most of the interviewed caregivers was not captured with the formal instruments used by the program.

Leslie Chang Evertson
April 2019

CAREGIVER OUTCOMES OF A DEMENTIA CARE PROGRAM

by

Leslie Chang Evertson

A project
submitted in partial
fulfillment of the requirements for the degree of
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APPROVED

For the California State University, Northern Consortium
Doctor of Nursing Practice:

We, the undersigned, certify that the project of the following student meets the required standards of scholarship, format, and style of the university and the student's graduate degree program for the awarding of the Doctor of Nursing Practice degree.

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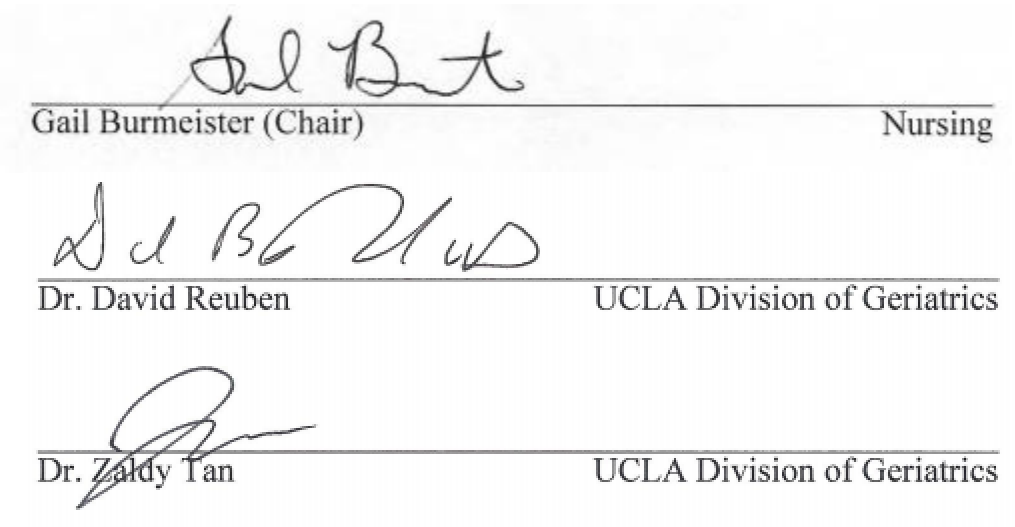

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CHAPTER 1: INTRODUCTION

There are 5.8 million people living with Alzheimer's dementia in the United States (Alzheimer's Association, 2019). The diagnosis of dementia requires a group of symptoms that includes changes in cognition and behaviors, severe enough to affect a person's ability to manage their activities of daily life (National Institute on Aging, 2017). 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 (American Psychiatric Association, 2017). In America, an estimated 18.5 billion hours of unpaid caregiving from friends and family members were spent caring for people with Alzheimer's and related dementias which is approximated to be worth $234 billion (Alzheimer's Association, 2019). Kasper, Friedman, Spillman and Wolff (2015) describe caregiving for people with dementia as especially demanding as the loss of function, behavioral symptoms, and extended course of the disease over many years cause continued challenges.

Family caregivers often become overwhelmed with the responsibilities of caring for a loved one with dementia and suffer from stress and depression (Alzheimer’s Association, 2019). They have difficulty knowing where to turn for education, guidance, and support. Appointments with their loved one’s physician are consumed with medication management and laboratory results, leaving little time to discuss dementia, its prognosis, behaviors, and the need for long-term planning. It is not uncommon for family caregivers to call the physician’s office frequently with questions regarding their loved one’s dementia. Community-based organizations can offer support and education but are not integrated 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 where a dementia care specialist (DCS), formerly called a dementia care manager, strives to meet this need. The DCS is an advanced practice nurse who understands the unique challenges of the person with dementia (PWD) and their family members. The DCS can spend the time families need to better understand dementia, how to recognize and manage the current stage of dementia and how to prepare for the future. Unlike a busy primary care provider, the DCS is available to the PWD and their family caregivers to provide dementia related medical management, linkages to community resources and health education about dementia.

Problem Statement

The UCLA ADC program was created in 2011 to provide comprehensive, coordinated dementia care for PWD and their family caregivers (Reuben et al., 2013). To date, the program has cared for over 2,600 PWD-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 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 community-based organizations (CBOs) and helps to connect dyads with local resources. Caregivers enrolled in the program for one year reported improved self-efficacy related to caring for their loved one with dementia, were less depressed, and suffered less caregiver strain (Jennings et al., 2015).

Outcomes data have been collected for the first 1,091 dyads enrolled in the ADC program, including dementia related behavioral severity scores as well as caregiver distress scores. Information on depression scores for both PWD and caregivers as well as functional status and caregiver strain are also obtained. At baseline, 13% of caregivers were depressed and 33% had high stress; those reporting higher levels of stress were more likely to be female, reported more depressive symptoms and cared for more functionally impaired patients with more behavioral problems (Reuben, 2016). At one year, despite disease progression, the PWDs' behavioral symptoms (e.g. agitation, irritability, apathy, and nighttime behaviors) improved by 12% and depressive symptoms were reduced by 24% (UCLA Alzheimer's and Dementia Care Program, 2016). In addition, at one-year, caregiver depression scores improved by 25%, distress related to behavioral symptoms improved by 24%, and caregiver strain improved by 11%. However, not all PWD-caregiver dyads enrolled in the UCLA ADC program appear to experience benefit. For example, although strain levels remained stable or decreased for 74% of caregivers, 26% reported increased caregiver stress. Similarly, 17% of caregivers enrolled in the ADC program reported worsening distress scores on the NPI-Q. To continually evaluate and attempt to improve the program, it is important to look at those dyads that did not benefit from participating in the program.

Purpose

This study evaluated the outcomes of the first 1,091 PWD-caregiver dyads who were recruited during the first 2 1/2 years of the program. Using a multidimensional instrument to measure caregiver burden (self-reported) and the severity of the PWD's behaviors (NPI-Q severity score), 151 caregivers (from PWD-caregiver dyads) have been identified who did not appear to have benefited from the ADC program after the first year of enrollment. These PWD-caregiver dyads had worsening dementia-related behaviors, the caregivers had worsening distress related to those behaviors, worsening caregiver strain, and depression. Caregivers were interviewed in order to gain insight on their experience in the program and to understand why the program did not seem to help them as well as what additional services might have been more helpful.

Prior research has looked at potential areas of clinical improvement as well as opportunities for reducing operating costs of the UCLA ADC program. This research study will help to conduct analyses that focus on the caregivers' perception of the ADC program. Based on the information learned from caregivers who did not benefit from participating in the ADC program, potential program modifications and improvements can then be made. For example, a segment of "sandwich" caregivers (i.e., adult children of PWD who are also caring for their own children) may not benefit from the usual caregiver support components (i.e., support groups). By identifying these less responsive subsets of caregivers, the program can be augmented (i.e., individual peer counseling by other caregivers who have been in similar situations) accordingly to better reach and help these groups.

Theoretical Framework

Informal caregivers often lack the awareness of community-based services, are reluctant to utilize them, find them unavailable, and have concerns of their affordability (Casado, van Vulpen, & Davis, 2011). When caregivers are caring for loved ones with dementia, they often become their surrogate decision-makers. It then becomes important to understand what the caregivers believe and understand themselves in order to provide both education and support. The health belief model (HBM) was developed in the 1950s and is one of the first theories about health behaviors (Glanz, Burke, & Rimer, 2018).

Glanz et al. explain that people are ready to act regarding their health, if they meet the following criteria:

1. Believe they are susceptible to the condition (*perceived susceptibility*)
2. Believe the condition has serious consequences (*perceived severity*)
3. Believe taking action would reduce their susceptibility to the condition of its severity (*perceived benefits*)
4. Believe the costs of taking action (*perceived barriers*) are outweighed by the benefits
5. Are exposed to factors that prompt action (*cue to action*)
6. Are confident in their ability to successfully perform an action (*self-efficacy*) (Glanz et al., 2018, p. 246)

Caregivers of PWD referred to the UCLA ADC program often experienced high levels of caregiver strain and were not confident that they were going to be able to manage caregiving or access help when needed (Jennings et al., 2015). By enrolling in a dementia care program, most caregivers understand that their loved one has dementia (perceived susceptibility). During the in-person visit and needs assessment, it may become apparent that the caregiver does not understand the severity or stage of their loved one's dementia (perceived severity). This may be where further education is needed to help the caregiver understand their loved one’s prognosis. Once this occurs, the caregiver may better understand, for example, how community-based services such as support groups or respite care can benefit both the PWD and themselves (perceived benefits). As Casado et al. (2011) noted, caregivers may believe that services are unavailable to them or are too costly, or are otherwise reluctant to utilize them (perceived barriers). By working with their DCS, gaining continuing education, resources and support, caregivers may feel empowered to utilize community-based services (cue to action). Over time, caregivers will gain trust and develop a relationship with their DCS, and feel more confident in their ability to care for their loved one with dementia (self-efficacy). This is consistent with the finding that, after one year in the UCLA ADC program, 62% of caregivers (from 19%) had greater self-efficacy in accessing resources for care and 94% of caregivers (from 43%) had greater self-efficacy in managing their loved one's behaviors (Jennings et al., 2015).

In order to effectively care for the PWD-caregiver dyad it is important for the dyad to understand that they are not alone in their dementia journey. The HBM provides a framework to understand the complexity of the DCS role. A dyad may present for the first time with the DCS with doubts about the accuracy of the dementia diagnosis. Before the DCS can move on to why continued participation in the ADC program is needed, the dyad must first understand why the diagnosis is accurate and what the diagnosis means to them. The DCS may illustrate perceived susceptibility by drawing a connection to another family member of the PWD who also had Alzheimer's disease. Perhaps the dyad understands the diagnosis but does not agree as to the stage of dementia: the DCS then needs to work on the dyad's perceived severity by providing examples of the PWD's symptoms such as short-term memory loss, changes in executive function, and safety issues. The DCS will ascertain where the dyad is regarding the HBM and tailor a dementia care plan that is comprised of medical, behavioral, and social recommendations. Occasionally, despite the DCS's personalized care plan for the dyad and ongoing care coordination, the PWD's behaviors will worsen in severity, as will the caregiver's distress, strain, and depression. This study attempts to identify the reasons why the UCLA ADC program was not beneficial for these dyads.

CHAPTER 2: LITERATURE REVIEW

People with dementia (PWD) and their families are at times reticent to acknowledge symptoms that are worrisome for dementia. Stites, Rubright and Karlawish (2018) found that the stigma of Alzheimer's disease caused people to believe that a diagnosis of Alzheimer's would put them at risk to be discriminated against at the workplace, excluded from their own medical decision-making, and at risk of either losing or having limited health insurance due to the results of brain imaging or genetic testing. As a result, a diagnosis is often delayed until symptoms can no longer be ignored. Once people are diagnosed with Alzheimer's disease or another dementia, over time they will need help living their everyday life. Most of this care is provided by informal family caregivers (Alzheimer's Association, 2019). When a PWD is in the hospital, emergency room, or skilled nursing facility, they are cared for by physicians, nurses, and nurses' aides. Outside of facilities, when a PWD seeks medical care, they will often see physicians, advance practice providers and social workers. Unfortunately, there is a shortage of geriatricians and trained social workers in the United States (Cottingham et al., 2014). With a limited number of trained professionals available to care for PWD, innovative models of care have had to be developed in order to meet the needs of the growing number of people being diagnosed with dementia every year.

Beyond the primary care or specialty clinic, PWD and their caregivers sometimes turn to community-based organizations to help answer their questions about dementia. Robinson, Buckwalter, and Reed (2013) found that although community services were available, 73% of caregivers did not attend support groups and 79% did not use services that provide respite. In addition, those caregivers that did not avail themselves of community-based services most often lived with the PWD and, were most often spouses. Casado et al. (2011) found that 91% of caregivers had never used respite care, and 95% had not utilized community-based programs or had participated in support groups. Except for the use of home health care likely related to Medicare coverage for these services post hospitalization and that most caregivers felt that they had no need for additional services.

Family caregivers and friends provide 83% of the unpaid care for older adults in the United States and approximately half of those older adults have a diagnosis of Alzheimer's or related dementia (Alzheimer's Association, 2019). Most of these caregivers, about two thirds, are women. Neither commercial insurance nor Medicare will pay a family member or friend to provide care for a loved one at home. In many states, if a PWD qualifies for Medicaid, the beneficiary can apply to receive funding to pay for private caregiving at home through approved registries or to pay the family member for the work of caregiving. Unfortunately, the hourly rate paid for by Medicaid is far lower than the average hourly cost for private caregivers. In addition, Medicaid will not provide enough hours to cover around-the-clock care. Hurd, Martorell, Delavande, Mullen, & Langa (2013) estimated that the out-of-pocket costs and utilization of nursing home care for PWD was $56,290 per person, per year. The approximate lifetime cost to care for a PWD including Medicare, Medicaid, out-of-pocket expenses, and the estimated value of family caregivers' time amounts to $350,174 (Alzheimer's Association, 2019). The societal and financial costs of dementia are like those of heart disease and cancer (Hurd et al., 2013).

Many programs have attempted to help PWD and their family caregivers cope with their common difficulties. In order to help identify those with dementia some novel approaches have been considered. For example, in Pennsylvania, Mavandadi et al. (2017) used insurance information, specifically a pharmaceutical assistance program, in order to identify people who had been prescribed psychotropic medications commonly used to treat dementia related symptoms, were over the age of 65, living in the community, and had been screened positive for dementia. They were able to identify 290 caregivers, and 150 were offered enhanced services which included telephone dementia care management and education over a period of 12 weeks. Only about half of these caregivers chose to enroll in enhanced services and roughly half of those met the researcher's criteria for engagement in the program leaving approximately 26% of caregivers completing the 12-week program. Researchers used the Zarit burden interview and found that increased caregiver burden was a significant factor for caregivers who enrolled in enhanced services. In supplemental analysis, researchers found that having adequate finances was shown to be associated with those who engaged in the enhanced service program which researchers postulated could mean more stability at home or perhaps could suggest that these caregivers may have more education and/or better access to other support services.

In North Dakota, the Dementia Care Services program employs social workers to provide services to PWD and their caregivers, with the goal of caregiver empowerment, reducing premature nursing home placement and decreasing acute health service use (Klug, Halaas, & Peterson, 2014). The care consultants are available by phone and can provide didactic in-person presentations and care consultations. Over a period of 42 months, the program worked with 1,750 caregivers: 55% needed in-person care consultations and the remaining 45% used the telephone information line. Using caregivers' self-reported data, researchers estimated that $39.2 million could have potentially been saved in delayed nursing home placement and an additional $0.8 million may have been saved in lower utilization of medical services. Klug et al. (2014) did not have a control group to compare the intervention to and the results were all self-reported at the convenience of the individual caregivers.

The Partners in Dementia Care (PDC) model is a care coordination program that uses social workers as care coordinators to support informal caregivers by providing education, preparation, and emotional support (Bass et al., 2013). In this study, one care coordinator worked within the Veterans Affairs Medical Center and one worked within an Alzheimer's Association chapter and both worked together to help provide improved dementia care coordination for the PWD and their family caregiver. The care coordinators provided assessments and action plans over the phone, through the mail, and via email. 508 veterans agreed to participate in the study and 486 of them had a caregiver who also agreed to participate. The researchers used comparison sites as a control group and had 187 caregivers compared to 299 in the intervention group. Bass et al. (2013) were able to show that at 6 months and 12 months caregivers had improvement in their unmet needs, strain, and depression.

To provide comprehensive dementia care two programs have been successful using advance practice providers and nurses in a care management role within the healthcare system in order to improve the quality of dementia care and reduce utilization. Eskenazi Health started the Healthy Aging Brain Center (HABC) in 2008, which originally utilized nurse practitioner care coordinators and have now transitioned to social workers and registered nurses as care coordinators, who collaborate with primary care providers to help PWD, depression, and mild cognitive impairment along with their family caregivers (Boustani, Alder, Solid, & Reuben, 2019). The HABC has created a new position called the Care Coordinator Assistant which is typically a non-licensed staff member who supports the care coordinator by meeting PWD or depression and their families in person or over the telephone. The original HABC model has proven a Medicare cost savings of $2,856 per person, per year. The new model, utilizing social workers and registered nurses as care coordinators, has shown a cost savings of $1,076 per person, per year (Boustani, 2019).

The UCLA ADC program was started in 2012 and utilizes nurse practitioners in the role of DCS providing comprehensive dementia care coordination in partnership with physicians (Reuben et al., 2013). The ADC program has also added a non-licensed role within the model called a Dementia Care Assistant who supports the DCS by working with PWD and caregivers over the phone and through email. The ADC program has shown a Medicare cost savings of $2,404 per person per year and was cost neutral after accounting for program implementation costs (Jennings et al., 2018).

The ADC program is the only advanced practice provider led dementia care program embedded within a healthcare system that co-manages with primary care. As such, there is no research on caregivers who did not benefit from this type of program. It is for this reason that this research is so important, as it will help to identify potential areas of improvement and continue to refine the model of care.

CHAPTER 3: METHODOLOGY

To better understand potential areas of improvement for the Alzheimer's and Dementia Care (ADC) program, we identified caregivers who were enrolled in the program and did not demonstrate clinical benefit on validated outcome measures assessing caregiver strain, depression, and distress related to behavioral symptoms of dementia. Research assistants completed semi-structured interviews over the telephone with caregivers. The interviews were transcribed and using content analysis, themes were selected, counted, and studied. This project was conducted at UCLA, a single site academic institution.

Project Design

As dementia is a progressive disease without a cure, identifying clinical benefit for either the person with dementia (PWD) or their caregivers can be challenging. Clinical benefit cannot be measured as an improvement in cognition or functional ability on the part of the PWD. Over time, dementia will rob a person of these possibilities. The ADC program supports not only the PWD but also their family caregiver. With this additional level of care, the ADC program hopes to see a reduction in the severity level of dementia-related behaviors in the PWD and a decrease in caregiver strain, depression, and distress.

The first 1,091 dyads have been followed longitudinally in the ADC program. Of those 1,091 dyads, 151 caregivers were identified as not benefitting from the ADC program based on these outcomes. In this qualitative study, these 151 caregivers were randomized, and 12 caregivers were consented over the telephone and completed semi-structured interviews using both open ended and structured responses. The transcribed interviews were analyzed by two researchers using content analysis and themes were identified. The study was approved by the California State University, Fresno Institutional Review Board.

Population and Sampling

Only family caregivers of a PWD who was enrolled in the ADC program between 2012 and 2014 were eligible. This is the timeframe that the first 1,091 PWD-caregiver dyads were enrolled, and longitudinal data were collected. Both PWD benefits and caregiver benefits were measured and dyads who did not benefit were identified.

In order to identify those PWD-caregiver dyads that did not benefit, the definition of what it means to have benefited from our program needed to be determined. The definition of benefit for a PWD after one year was determined by improvement in their Neuropsychiatric Inventory Questionnaire (NPI-Q) severity score or maintaining low symptoms at 1 year. The NPI-Q is a validated survey that measures the caregiver’s observation of 12 dementia-related behaviors: delusions, hallucinations, agitation, depression, anxiety, elation, apathy, disinhibition, irritability, motor disturbance, nighttime behaviors, and changes in appetite (Kaufer et al., 2000). The highest NPI-Q severity score possible is 36, the higher the score, the more severe the distress. Benefit on the NPI-Q severity scale was defined as having a 1-year score of $\leq$ 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 (Mao, Kuo, Cummings, & Hwang, 2015).

Caregiver benefit was measured using the Dementia Burden Scale-Caregiver (DBS-CG) (Reuben et al., 2019). The DBS-CG is a composite of the NPI-Q distress scores, Modified Caregiver Strain Index (MCSI), and Patient

Health Questionnaire-9 (PHQ-9) scales (Peipert et al., 2018). The NPI-Q distress score ranges from 0-60, the higher score the higher the severity of caregiver distress related to the dementia related symptoms mentioned previously (Kaufer et al., 2000). The MCSI is a 13-item validated tool describing symptoms related to informal caregiver strain and is scored from 0-26, the higher the score, the more severe the strain (Thornton & Travis, 2003). The PHQ-9 is a validated tool to measure patient depression severity, with scores that range from 0-26, the higher the score, the more severe the symptoms of depression (Kroenke, Spitzer & Williams, 2001). The DBS-CG benefit is scored using a possible range of 0-100. DBS-CG benefit was defined as having a 1-year score of $\leq$ 17.8 or having a baseline score of > 22.8 and improving by at least 5 points. Defining benefit in this manner identified those who maintained low symptoms and had improved symptoms from the program (Reuben et al., 2019).

Family caregivers who did not benefit, of PWD who also did not benefit from the program, were identified as possible participates in the study. 151 PWD-caregiver dyads were selected based on not having benefited from being enrolled in the program after one year.

The 151 caregivers were first randomized. They were then identified by gender (male/female) and relationship to the PWD (spouse/child). Using stratified purposeful sampling to reflect the proportion of caregiver type that were represented in the 151 caregivers, the research assistants called caregivers until they completed a total of 12 interviews: 7 interviews with daughters, 2 interviews with wives, 2 interviews with husbands, and 1 interview with a son.

Data Collection

Research assistants called caregivers and obtained consent over the telephone (See Appendix A). If consent was obtained, the research assistant proceeded with the semi-structured interview, starting with an introduction (See Appendix B) followed by the semi-structured interview using the script provided (See Appendix C). A chart abstraction was completed by the research assistant to determine what interventions, referrals, and services were recommended by the dyads' DCS over the course of the first year of enrollment.

Data Analysis

All telephone interviews were recorded and transcribed verbatim for analysis purposes. 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 (Bengtsson, 2016). 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 is 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.

CHAPTER 4: RESULTS AND DISCUSSION

Results

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 Alzheimer's and Dementia Care (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." Based on the answers of those that agreed to participate in the semi-structured interview, seven themes were identified. These themes included: caregiver perception of being provided recommendations that did not match perceived care needs, existence of 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, received behavioral recommendations that the caregiver felt did not work, and dementia expert had poor rapport with caregivers. Example caregiver responses have been selected for further discussion and additional caregiver responses are located in Table 1.

Table 1

Additional Caregiver Responses Identified by Theme and Subcategory

Theme	Subcategories	Selected Quotes
Recommendations that did not match perceived care needs	Safety Recommendations	*"… 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)* *"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)*

(continued)

(continued)

Theme	Subcategories	Selected Quotes
	Support Groups	*"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)*
	Advance Care Planning	*"The whole advance directive is very important, but I had done all of that while I was still in Fresno." (daughter)* *"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)*
	Specialist Recommendations	*"There was no reason for my mother to go to a psychiatrist…There was no reason." (daughter)*
	Transportation	*"I don't think we really took advantage of transportation services." (daughter)* *"It [transportation recommendation] wasn't [helpful] because we engaged the caregiver…and she drives us all over when we have to go." (husband)*
	Adult Day Care	*"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)* *"Not really [helpful] because…the daycares I have to pay for…you know…and we are not in the position…" (wife)*
	Too frequent visits	*"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)*
	Support groups weren't helpful	*"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)*

(continued)

(continued)

Theme	Subcategories	Selected Quotes
Barriers to accessing and utilizing care and services	Parking	*"…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)*
	Lack of respite care	*"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)*
	Location	*"…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)*
	Feeling overwhelmed	*"… 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)* *"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)*
	Technology	*"…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)*
	Language	*"…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)*

(continued)

(continued)

Theme	Subcategories	Selected Quotes
Care needs varied by dementia stage	Late stage dementia	*"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)* *"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)*
Needed services not offered by the ADC	Counseling	*"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)*
	Long-term care options	*"…if you guys had a list of board and cares versus big fancy…" (daughter)*
Needed more education or support	Education	*"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)*
	Access to DCS	*"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)*

(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)*

Recommendations did not Match Perceived Care Needs

The most common theme among the caregivers interviewed was the feeling that recommendations made by the dementia care specialist (DCS) did not match perceived care needs or were unneeded. Examples of these recommendations include: advance care planning, recommendations to specialists, transportation, and adult day care. Most frequently caregivers cited what they felt were unnecessary safety recommendations such as home safety modifications or a Safe Return bracelet. Some caregivers felt they had already adequately addressed safety issues and some lacked insight into risks. For example, even when their loved one 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 recommendations were the next most commonly cited unneeded recommendation. Caregivers expressed several reasons they felt support groups did not meet their perceived needs and 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 not ready…we not ready…when the time comes, when I am no longer able to handle 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 Services

Caregivers identified several perceived barriers that may have prevented the dyad from benefiting from the program, including difficulties with transportation, location of services, lack of respite care, challenges with computer-based resources, and services not in the patient’s primary language. One caregiver described trouble getting to the appointment due to expensive parking and difficulty with the 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 utilizing support groups and attending 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 their loved one, which in and of itself was a barrier. One daughter explained the difficulty she had getting to support groups:

> … 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

The appropriateness of DCS recommendations in relation to the person with dementia's (PWD) stage of dementia appeared as a theme amongst dyads who did not seem to benefit from the ADC program. From one daughter's perspective, getting help earlier would have been ideal but getting assistance even later in her mother's dementia journey was 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 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 their loved one’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 rather than a group setting such as a support group, as it would have been more helpful for her and that more education was needed in order to understand the disease better. 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 access to the DCS 24 hours a day, seven days a week in case of emergency. 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

There were three caregivers that were interviewed that did not feel that the ADC program was beneficial for them, two daughters and one wife. Feeling that the ADC program needed to provide more education or support was common among them. 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 regularly on the phone… even though they can't come and visit…like regularly call the patient family because every new changes happen 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.

Expert had Poor Rapport with Caregivers

In one interview a caregiver noted that she did not appreciate her interaction with a DCS and considered her 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

Nonpharmacological behavioral modifications are often taught to family caregivers as a way to manage their loved one's dementia related behaviors. Gitlin, Kales, and Lykestsos (2012) describe nonpharmacological treatments for behavioral symptoms as caregiver education and training, and specific approaches to behaviors. Examples include maintaining a daily schedule, improving communication skills, and learning to redirect or reorient the PWD. 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'.

Discussion

This qualitative study attempted to identify reasons why some PWD 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 measures of PWD behavioral symptoms and caregiver strain, distress, and depression. Three quarters of the caregivers interviewed felt that their participation in the ADC program was beneficial despite not demonstrating clinical benefit on these measures, suggesting there are benefits to dementia care management that are not well captured by the constructs of caregiver strain, caregiver depression, and caregiver distress due to behavioral symptoms. Other benefits articulated by caregivers frequently related to the many roles of the DCS and the sense of security and peace-of-mind having access to the DCS provided. Caregivers reported the DCS serving as a dementia-content expert and educator, emotional support person, counselor, crisis manager, advocate, and care navigator. Future work examining the outcomes of dementia care management should further explore each of these roles of the DCS and how they relate to caregiver outcomes. Additionally, inclusion of broader measures of caregiver benefit in future studies may provide a more comprehensive understanding of the benefits of dementia care management. Measures such as caregiver self-efficacy and competency, role satisfaction and positive aspects of caregiving, perception of emotional and social support, and attainment of personalized goals related to the caregiving role, may be particularly relevant.

When asked specifically about the recommendations made by their DCS, caregivers perceived some of the recommendations as unneeded or unhelpful, but did not describe them as detrimental. Caregivers also described feeling overwhelmed, which is consistent with estimates that 59% of family caregivers that care for a loved one with dementia described their caregiver stress as high to very high (Alzheimer’s Association, 2019). The 3 caregivers interviewed who did not feel that their participation in the ADC was beneficial identified the need for more information and education about dementia, the need for care recommendations and services more closely linked to their loved one’s stage of disease, and a feeling that the program did not meet their expectations overall.

Spending additional time to clarify caregiver expectations and perceived needs and barriers may improve the ability of the DCS to provide recommendations that caregivers feel empowered to enact (step 6 the Health Belief Model). If a dyad does not perceive the benefits of dementia care management, dyad education about dementia and support needs to be provided as the next step. If a caregiver is too overwhelmed to obtain help in the community or to learn more about their loved one’s disease and its progression, there may not be sufficient buy-in for the caregiver to see the benefit of a dementia care program.

The program collected outcomes data for the first 1,091 PWD-caregiver dyads. Only 645 of the 1,091 dyads (59%) returned for their first-year annual visit (Reuben et al., 2019). This loss of follow-up is likely multifactorial, including death, patients becoming homebound, change in insurance status, or moving out of area. However, another possible reason may be that dyads who did not return did not feel that the program was beneficial to them.

Changes made to the program over the years may have addressed some of the feedback provided by the caregivers. For example, in the second year of the program vouchers were made available for PWD and their family caregivers that were enrolled in the program 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 however had previously remained out of reach for many due to financial reasons. Additionally, home visits were incorporated into the care model to better reach homebound patients. Support groups focused on the needs of 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.

Any new model of care needs to be evaluated longitudinally. A strength of this study is that outcome measures were used to objectively identify dyads that did not seem to benefit from the ADC program. Having longitudinal data for 1,091 dyads allowed for retrospective data analysis. Using the themes identified from the completed semi-structured interviews, a survey tool has been developed to better understand and identify potential areas of improvement for the ADC program. An additional 38 caregivers will be surveyed and together with the initial 12 interviews, a total of 50 caregivers’ responses will help to achieve this goal.

Limitations

Several limitations of this study are worth noting. One limitation is that beyond the quantitative data that identified the dyads that did not benefit from being enrolled in the ADC program, the semi-structured interviews were based on self-report and relied on the caregiver being able to remember their experience from as many as six years ago (recall bias). There is also the possibility that, since the research assistants identified themselves as working with the ADC program, caregivers potentially may want to tell them what they think the program would want to hear (social desirability bias). The study only included 12 caregivers, and a larger sample size may have provided additional potential areas of improvement. However, purposive sampling was used to ensure a broad range of caregiver respondents. The ADC program primarily sees patients in Los Angeles and Ventura counties. If the program were instituted at other sites, the feedback from caregivers would likely reveal variations based on their local communities. This study sought caregivers of dyads that did not benefit, which could only be determined after they returned for their one-year annual visit. The researchers were unable to capture a segment of dyads who did not agree to come back for an annual visit. Some of these dyads may not have benefited from the program, and in fact their lack of continued participation may have been an indication of that and their feedback could have been helpful.

CHAPTER 5: CONCLUSION

The UCLA ADC program was born out of the need to improve dementia care for PWD and their family caregivers. DCSs attempt to meet the needs of the PWD and their family caregivers by working with their treating physicians to manage their dementia-related medical care, identify community resources, make referrals and recommendations, and spend time educating and supporting the dyad. Despite this additional level of intervention, the ADC program will not be able to meet everyone’s needs. Despite having been identified as having had no clinical benefit from participating in the program, 9 of those 12 caregivers did feel that the program was beneficial. This dichotomy highlights that perceived benefit for most of the interviewed caregivers was not captured with the formal instruments used by the program. Additional research is needed and a telephone survey has been developed which utilizes phone interviews to ask more specific questions to help better understand how the ADC program might be improved. The remaining caregivers that have been identified as not having benefited from the ADC program will be surveyed. Continuing to seek ways to improve this new model of care will serve to benefit not only the current program at UCLA but also will help to provide expert guidance and support as the model is adopted in healthcare systems across the country.

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APPENDICES

APPENDIX A: TELEPHONE CONSENT

I am calling to ask your opinions about the value of the services provided by the UCLA Alzheimer's and Dementia Care program. Your participation in this research study is voluntary and you may refuse or discontinue participation at any time without penalty. You and your loved one have been identified as possibly not benefiting from the Alzheimer's and Dementia Care program. If you agree to participate, I will ask you to complete a telephone interview with me, which will take approximately 15 minutes. Our conversation will be recorded for research purposes and your confidentiality will be maintained by removing any identifying information from the information collected. Your participation will help the Alzheimer's and Dementia Care program improve and better serve our patients and their families. If you have any questions you can contact Leslie Evertson, GNP or Katherine Serrano, MPH 200 UCLA Med Plaza number 365 a Los Angeles, CA 90095 at 310-319-3222. You can reach the UCLA office of human research protection program at 310-825-7122. Would you like to proceed?
Yes/No.

If yes – thank the caregiver and proceed.
If no – ask if the caregiver would be willing to participate in a short survey in the future.

APPENDIX B: SEMI-STRUCTURED INTERVIEW INTRODUCTION

Good morning/afternoon,

Hello, my name is [interviewer] and I am a [title] in/for the UCLA Alzheimer's and Dementia Care program. I am calling you because your loved one is *enrolled/was previously enrolled* in our program. You may remember having a face-to-face visit with your dementia care manager and then receiving information regarding support groups, education, respite, counseling, and dementia related behavior management.

APPENDIX C: SEMI-STRUCTURED INTERVIEW

Before we start, can you tell me about your experience with the UCLA Alzheimer's and Dementia Care Program?

Can you tell me more about that?

Would you mind explaining what you mean by that?

Overall, did you find your participation with the program to be valuable? (Yes or No)

If yes, how so? If no, why not?

Did you feel that there were any barriers to the program helping you? (Yes or No)

If yes, what kind? If no, why?

On a scale of 1 through 5, 1 meaning not likely and 5 meaning definitely, how likely are you (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)?

Tell me why you would [*not likely* -> *definitely*] call the DCM?

During the first year that you were in the program, [Dementia Care Manager's name] made some recommendations and referrals. I would like to ask you about these specifically.

Your Dementia Care Manager made <u>medical</u> recommendations for your loved one such as [recommendations made in initial assessment]. **Did you find these recommendations valuable?** (Yes or No) If yes, why? If no, why not?

Your Dementia Care Manager made <u>advance care planning</u> recommendations for your loved one such as [recommendations made in initial assessment]. **Did you find these recommendations valuable?** (Yes or No) If yes, why? If no, why?

Your Dementia Care Manager offered you recommendations in regards to <u>safety</u> such as [recommendations made in initial assessment]. **Did you find these recommendations valuable?** (Yes or No) If yes, why? If no, why?

Is there anything that you would change about these recommendations? (Yes or No)
If yes, what? If no, why?

Your Dementia Care Manager offered you recommendations in regards to <u>training and education</u> such as [recommendations made in initial assessment]. **Did you find these recommendations valuable?** (Yes or No) If yes, why? If no, why?

Is there anything that you would change about these recommendations? (Yes or No)
If yes, what? If no, why?

Your Dementia Care Manager offered you recommendations for **<u>support and services</u>** **for you, such as** [recommendations made in initial assessment]. **Did you find these recommendations valuable?** (Yes or No) If yes, why? If no, why?

Is there anything that you would change about these recommendations? (Yes or No)
If yes, what? If no, why?

Would any specific services have been helpful that were not offered by the Dementia Care Manager? (Yes or No) If yes, what? If no, why?

Are there any areas regarding your loved one's dementia care that you feel were not addressed by the Dementia Care Manager? (Yes or No) If yes, what? If no, why?

Thank you for participating in this interview about the Alzheimer's and Dementia Care program.