

Factors Associated with Supportive Care Service Use Among California Alzheimer's Disease Patients and Their Caregivers

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Abstract.

Background: Existing literature on factors associated with supportive care service (SCS) use is limited. A better understanding of these factors could help tailor SCS to the needs of frequent users, as well as facilitate targeted outreach to populations that underutilize available services.

Objective: To investigate the prevalence of SCS use and to identify factors associated with, and barriers to, service use.

Methods: California Alzheimer's Disease Center patients with AD ($n = 220$) participated in the study from 2006–2009. Patients and their caregivers completed assessments to determine SCS use. Cognitive, functional, and behavioral status of the patients were also assessed. A two-part hurdle analysis identified 1) factors associated with *any* service use and 2) service use frequency among users.

Results: Forty percent of participants reported using at least one SCS. Patients with more impaired cognition and activities of daily living and more of the following: total number of medications, comorbid medical conditions, and years of education were more likely to use *any* SCS ($p < 0.05$). Factors associated with more frequent SCS use included younger age, more years of education, older age of AD onset, female gender, and having a spouse or relative for a caregiver ($p < 0.05$). Caregivers frequently indicated insufficient time as a reason for not receiving enough services.

Conclusion: Factors associated with any SCS use mostly differed from those associated with SCS frequency, suggesting different characteristics between those who initiate versus those who continue SCS use. Our findings highlight the importance of targeted education on services and identifying barriers to long-term SCS use.

Keywords: Activities of daily living, Alzheimer's disease, caregiver burnout, dementia, family caregivers, respite care, spouse caregivers, support group

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INTRODUCTION

Approximately 5.7 million Americans are currently afflicted by Alzheimer's disease (AD), with the number expected to more than double to 13.8 million by 2050 in people 65 years and older [1]. It is widely known that AD creates significant challenges and stressors for patients and their caregivers, and that the burden typically increases over the course of disease progression. Caregiving responsibilities are largely shouldered by spouses and children of AD patients [2]. The documented increase in the prevalence of AD will be accompanied by a higher demand for caregivers and an increase in the number of individuals who experience burden associated with their caregiving roles.

Supportive care services (SCS), including patient and caregiver support groups, adult day services, overnight residential respite, and family respite, provide assistance to those in need of support in their caregiving responsibilities. Typical benefits of support groups include education, sharing the illness experience, camaraderie among attendees, and improved coping and acceptance of the diagnosis [3, 4]. Adult day services provide activities for patients in a safe environment while allowing caregivers time to do other things. Additional benefits to this SCS are decreased reported frequencies of behavioral problems and decreased time spent by caregivers managing behavioral problems in patients with AD [5]. Similarly, respite care allows caregivers a short break from their caregiving role and can provide temporary relief from stress and worry as well as an opportunity for caregivers to engage in self-care activities [6]. Access to SCS is available through multiple channels including government agencies (Department of Veterans Affairs, community centers), private companies, and non-profit organizations (Alzheimer's Association).

Previous research has shown that, in addition to serious medical or health events for patients and caregivers [7], factors such as difficulty managing problem behaviors in patients and the inability to provide adequate care for the patient are among the top reasons for long-term care placement [8]; whereas, there is evidence that improving caregiver well-being can delay time to placement into a long-term care setting [9]. It is likely that SCS use may help mitigate some of these contributing factors, reduce caregiver burden, and potentially enable patients to remain in their own homes for

longer periods of time. Delaying patient placement into a long-term care setting has several advantages including better outcomes for patients such as slower rate of decline [10, 11], and significant cost savings for families and the overall healthcare system [12].

Because of the significant benefits of SCS, this paper aims to investigate the prevalence and frequency of SCS use among AD patients and caregivers and to identify factors associated with and barriers to SCS use. While much of the existing literature focuses on various approaches to providing services and the effectiveness of support services [4, 9, 13–17], less work has examined associations between patient or caregiver characteristics and service utilization [18, 19]. Through identification of characteristics that promote or hinder SCS utilization, targeted outreach and intervention programs can be developed to increase SCS engagement, improve quality of life, and prolong time to placement.

MATERIALS AND METHODS

Sampling and procedures

The California Alzheimer's Disease Centers (CADCs), formerly Alzheimer's Disease Research Centers of California, collaborate to create a central pool of information on new and returning patients who receive diagnostic evaluation and follow-up services at the Centers throughout California each year. A total of 220 patients were recruited from two CADCs between 2006 and 2009 as part of a collaborative protocol exploring SCS use. Study Site A serves an urban area of the state, while Study Site B serves rural communities. Patients were eligible to enroll in this study if they had a prior diagnosis of Probable, Possible, or Mixed Alzheimer's disease [20] and had a caregiver who was willing to participate.

Potential patients and their caregivers were recruited for this study either during a return visit to one of the participating Centers (Sites A and B) or after an on-site support group meeting (Site A only). This study was approved by the IRBs at both institutions.

Demographics

Demographic data for patients, including years of education, ethnicity, gender, age at study baseline, age of symptom onset, marital status, and the

caregiver's relationship to the patient were collected upon enrollment and verified using the CADC Minimum Uniform Dataset (MUDS). The MUDS was a common data collection tool used by all collaborating CADC sites between 1985 and 2009. Data were centrally processed by the Institute for Health and Aging (IHA) at the University of California, San Francisco and have been utilized in several collaborative CADC studies [21–23]. Caregiver gender and each patient's total number of current prescribed and over-the-counter medications, vitamins, herbs, and supplements (herein referred to as medications), and co-morbid medical conditions, as determined by a set of 22 co-morbid medical condition items on the MUDS (see Supplementary Material 1), were also obtained at enrollment.

Measures

With the exception of the Mini-Mental State Exam (MMSE), the caregiver provided all responses to the measures.

Assessment of supportive care services use: The Activities Questionnaire

Patient and caregiver use of SCS were assessed using the Activities Questionnaire (see Supplementary Material 2), which was developed by one of the authors (H.D.D.) and used here for the first time to assess frequency of service use, the level of need met by each service, and barriers to receiving sufficient services. Caregivers completed this questionnaire independently to document SCS use over the 6-month period preceding the enrollment into the study. Responses were reviewed by clinical staff and assistance was provided if requested or required. The questionnaire focuses on five SCS: 1) patient support groups, 2) caregiver support groups, 3) adult day-care, 4) overnight residential respite care, and 5) the use of family members other than the caregiver for respite. Respite care refers to temporary placement in a nursing home, trained professionals coming into the home to provide short-term care (overnight residential respite), and family members who come into the home to provide short-term care (family for respite) to allow caregivers time away from their caregiving role. Caregivers reported on the presence or absence of service use as well as the frequency of use over the preceding six months. Service use frequency was summed across all five services to create a composite primary outcome variable for estimated total support-

ive care service use.¹ Ranges for the five services are as follows: 1) patient support groups (0–26), 2) caregiver support groups (0–26), 3) adult day services (0–130), 4) night respite (0–7), and 5) family respite (0–7). The range for the composite total SCS use is 0–196. Caregivers also indicated the level of need that was met by checking one of the following options: “Yes, I got all the services I needed”, “Yes, I got most of the services I needed”, or “No, I did not get enough of the services I needed”. If not enough services were received, they were asked to check all of the applicable reasons, including financial concerns, lack of time, difficulty locating resources, transportation difficulty, and other. Respondents could provide details of other reasons, if applicable.

Patients' cognitive and functional status

The 30-point MMSE [24], administered to the patient, and the 17-point Blessed Roth Dementia Rating Scale (BRDRS) [25], completed in consultation with the caregiver, assessed cognitive and functional status, respectively. Higher scores on the BRDRS and lower scores on the MMSE reflect increased impairment.

Statistical analyses

Frequencies and means were calculated (overall and by site) for demographic variables and the following measures: MMSE, BRDRS, comorbid medical conditions, and medication count. Site differences were examined using Wilcoxon Rank Sum tests for continuous variables and chi-squared (or Fisher's exact tests, where appropriate) for categorical variables. For the primary analysis, we implemented a regression model to examine factors associated with estimated total services used. Due to the fact that many participants did not use services, we elected to use zero-inflated regression models. We considered zero-inflated Poisson, zero-inflated negative binomial, and hurdle regression—all of which characterized zeroes using a logit function—and compared models via a likelihood ratio test, Akaike

¹For example, a response of “More than once a month” for frequency of caregiver support group attendance was assumed to be two sessions per month and was converted to a 6-month frequency of 12 sessions. If a respondent also indicated use of adult day care services 1-2 times per week, an average of 1.5 days/week was used to obtain the 6-month frequency (1.5 sessions/week * 26 weeks = 39 sessions). The total service use over the 6-month period would be 12 caregiver support group sessions + 39 adult day care sessions = 51.

Information Criterion (AIC), and Bayesian Information Criterion (BIC) as recommended by Long and Freese [26]. These models are ideal when data contain a preponderance of zeroes (in this case, zero services used; see [27] for more detail on each of these approaches). Age, age of onset, highest level of education attained, caregiver group (spouse, other relative, other), BRDRS, and MMSE were entered simultaneously as independent variables into the regression model. Marital status was excluded from the primary analysis due to its significant association with the caregiver variable (Spearman's $\rho=0.719$, $p<0.001$). Despite limitations in power caused by subsetting the data by service type, an exploratory analysis was also performed in which caregiver-recipient (caregiver support group, paid caregiver respite, and family respite) and patient-recipient (patient support group and adult daycare) were modeled separately. Due to the fact that participants were nested within separate study sites, standard errors and subsequent p -values were adjusted via cluster robust

standard errors (for study site) in the regression models [28]. All statistical tests were conducted using SAS 9.4, with the exception of the regression models, which were conducted in Stata v15.1. Statistical significance was evaluated at a two-sided alpha of $p=0.05$.

RESULTS

Baseline characteristics

Patient demographics overall and by site are summarized in Table 1. A comparison of patient demographics by site revealed that patients from Site A (the urban area) had significantly higher levels of educational achievement ($Z=5.02$, $p<0.001$) and comorbid medical conditions ($Z=5.77$, $p<0.001$) upon enrollment into the study compared with patients from Site B (the rural area). There were significant relationships between study site and the following categorical variables: patient gender ($\chi^2 [1]=5.24$, $p=0.022$), diagnosis ($\chi^2 [2]=15.29$, $p<0.001$),

Table 1
Patient Characteristics Overall and by Site

	Overall (<i>n</i> = 220) <i>n</i> (%)	Site A (<i>n</i> = 109) <i>n</i> (%)	Site B (<i>n</i> = 111) <i>n</i> (%)	χ^2	<i>p</i>
<i>Diagnosis (n = 220)</i>					
Probable AD	139 (63.18)	72 (66.06)	67 (60.36)		
Possible AD	49 (22.27)	14 (12.84)	35 (31.53)		
Mixed AD	32 (14.55)	23 (21.10)	9 (8.11)	15.29	<0.001*
<i>Patient Gender (n = 220)</i>					
Female	120 (54.55)	51 (46.79)	69 (62.16)		
Male	100 (45.45)	58 (53.21)	42 (37.84)	5.24	0.022*
<i>Caregiver Gender (n = 201)</i>					
Female	137 (68.16)	71 (65.14)	66 (71.74)		
Male	64 (31.84)	38 (34.86)	26 (28.26)	1.00	0.317
<i>Caregiver^a (n = 218)</i>					
Spouse or Spouse Equivalent	118 (54.13)	77 (70.64)	41 (37.61)		
Other Family Member/Relative	91 (41.74)	30 (27.52)	61 (55.96)		
Other	9 (4.13)	2 (1.83)	7 (6.42)		<0.001*
<i>Marital Status (n = 214)</i>					
Married	144 (67.29)	82 (78.10)	62 (56.88)		
Other	70 (32.71)	23 (21.90)	47 (43.12)	10.94	0.001*
<i>Ethnicity (n = 220)</i>					
Caucasian	171 (77.73)	83 (76.15)	88 (79.28)		
Non-Caucasian	49 (22.27)	26 (23.85)	23 (20.72)	0.31	0.577
	Mean (SD)	Mean (SD)	Mean (SD)	Z^b	<i>p</i>
Age (<i>n</i> = 220)	79.04 (6.96)	79.33 (7.14)	78.76 (6.80)	0.63	0.527
Age at symptom onset (<i>n</i> = 216)	72.74 (7.82)	73.11 (8.29)	72.36 (7.33)	-0.09	0.356
Education, years (<i>n</i> = 220)	13.90 (3.39)	15.04 (2.95)	12.78 (3.44)	5.02	<0.001*
MMSE (<i>n</i> = 203)	19.99 (6.10)	19.55 (6.23)	20.41 (5.98)	-1.06	0.229
BRDRS (<i>n</i> = 211)	5.00 (3.57)	5.30 (3.49)	4.69 (3.65)	-1.63	0.103
Comorbid Conditions (<i>n</i> = 214)	3.02 (1.73)	3.70 (1.70)	2.37 (1.51)	5.77	<0.001*
Medication Count (<i>n</i> = 214)	6.27 (3.72)	6.58 (4.04)	5.96 (3.38)	0.87	0.382

SD, standard deviation; MMSE, Mini-Mental State Examination; BRDRS, Blessed Roth Dementia Rating Scale.

^aFisher's Exact Test; ^bWilcoxon Rank Sum Test; * $p<0.05$.

Table 2
Use of Supportive Care Services Overall and by Site

	Overall (n = 220) n (%)	Site A (Urban) (n = 109) n (%)	Site B (Rural) (n = 111) n (%)
Patient Support Group	27 (12%)	21 (19%)	6 (5%)
Caregiver Support Group	50 (23%)	33 (30%)	17 (15%)
Adult Day Care	34 (15%)	28 (26%)	6 (5%)
Overnight Respite	13 (6%)	11 (10%)	2 (2%)
Family for Respite	30 (14%)	15 (14%)	15 (14%)
1 or More Service Used	88 (40%)	56 (51%)	32 (29%)

marital status ($\chi^2 [1] = 10.94, p = 0.001$), and caregiver (Fisher's exact test: $p < 0.001$). Specifically, mixed AD was more commonly diagnosed at Site A, whereas possible AD was more commonly diagnosed at Site B. Caregivers were much more likely to be spouses at Site A versus other family members or "other" (i.e., friend or non-relative) at Site B, and patients were more likely to be male and married at Site A. No other significant differences were found.

Supportive care service use

Forty percent of participants reported using one or more SCS in the 6-month time period prior to enrollment. Further breakdown of the use of specific services by site is illustrated in Table 2 and frequency of service use for all services over the six months prior to data collection is illustrated in Fig. 1 The majority of caregiver and patient support group users attended monthly or more (70% and 67%, respectively). Most adult day care users attended weekly or more (88%). Night respite was used less frequently with 75% attending 0–3 times. Finally, family respite users were split equally between 0–3 times and 4 or more times during the previous six months.

Regression model to examine factors associated with frequency of service use

Based on likelihood ratio tests, as well as AIC and BIC, the hurdle model had the best model fit and was therefore used for the analysis.² Briefly, hurdle models consist of a two-part estimation procedure, by way of implementing separate regressions

for separate distributions [27]. For the current study, the hurdle model incorporated a logistic regression (to model absence or presence of a service used) and exponential regression (to model the number of times services were used). Table 3 provides the results of the hurdle analysis. Significant factors associated with any service use were different from factors associated with frequency of total service use. With regard to service users, individuals with more years of education were more likely to use services (Odds Ratio [OR] = 1.06, $p = 0.017$) and patients with higher MMSE scores (i.e., less severe cognitive impairment) were less likely to use services (OR = 0.95, $p = 0.003$). Similarly, higher BRDRS scores (i.e., more functional impairment) were associated with increased odds of using one or more services (OR = 1.06, $p = 0.003$). As the number of medications and co-morbid medical conditions increased, so did the likelihood that services would be used (OR = 1.02, $p = 0.001$, and OR = 1.14, $p = 0.008$, respectively). Among those who used services (i.e., the exponential regression within the hurdle model), female patients used them more frequently than male patients (IRR = 1.39, $p = 0.043$). Individuals with a non-family member caregiver used significantly fewer services (IRR = 0.28, $p < 0.001$). Less frequent service use was associated with greater patient age (IRR = 0.99, $p < 0.001$); however, greater age at symptom onset was associated with an increase in the number of services used (IRR = 1.04, $p = 0.004$). Finally, more years of education was associated with more services used (IRR = 1.08, $p < 0.001$).

Caregiver and patient service use

Because specific services may be more targeted to patients or caregivers, an exploratory analysis was undertaken in order to estimate factors that contributed to utilization of services geared toward the two groups. Patient-recipient services included patient support groups and adult day care, while caregiver-recipient services included caregiver support groups, night respite, and family for respite. These analyses showed that, while the pattern found in the main analyses held for education, MMSE, and the number of medications the patient was taking, the odds of using a caregiver service were lower for caregivers of female patients (OR = 0.44, $p < 0.001$) and higher for patients with higher BRDRS scores (OR = 1.14, $p < 0.001$) (see Supplementary Table 1). The odds of using patient services were higher for patients with more reported comorbid

²Zero-inflated Poisson regression: AIC = 3973.44, BIC = 3976.66; zero-inflated negative binomial regression: AIC = 838.22, BIC = 841.44; hurdle regression: AIC = 723.12, BIC = 729.56. Hurdle versus zero-inflated Poisson $\chi^2 = 3252.32, p < 0.001$; hurdle versus zero-inflated negative binomial $\chi^2 = 117.01, p < 0.001$.

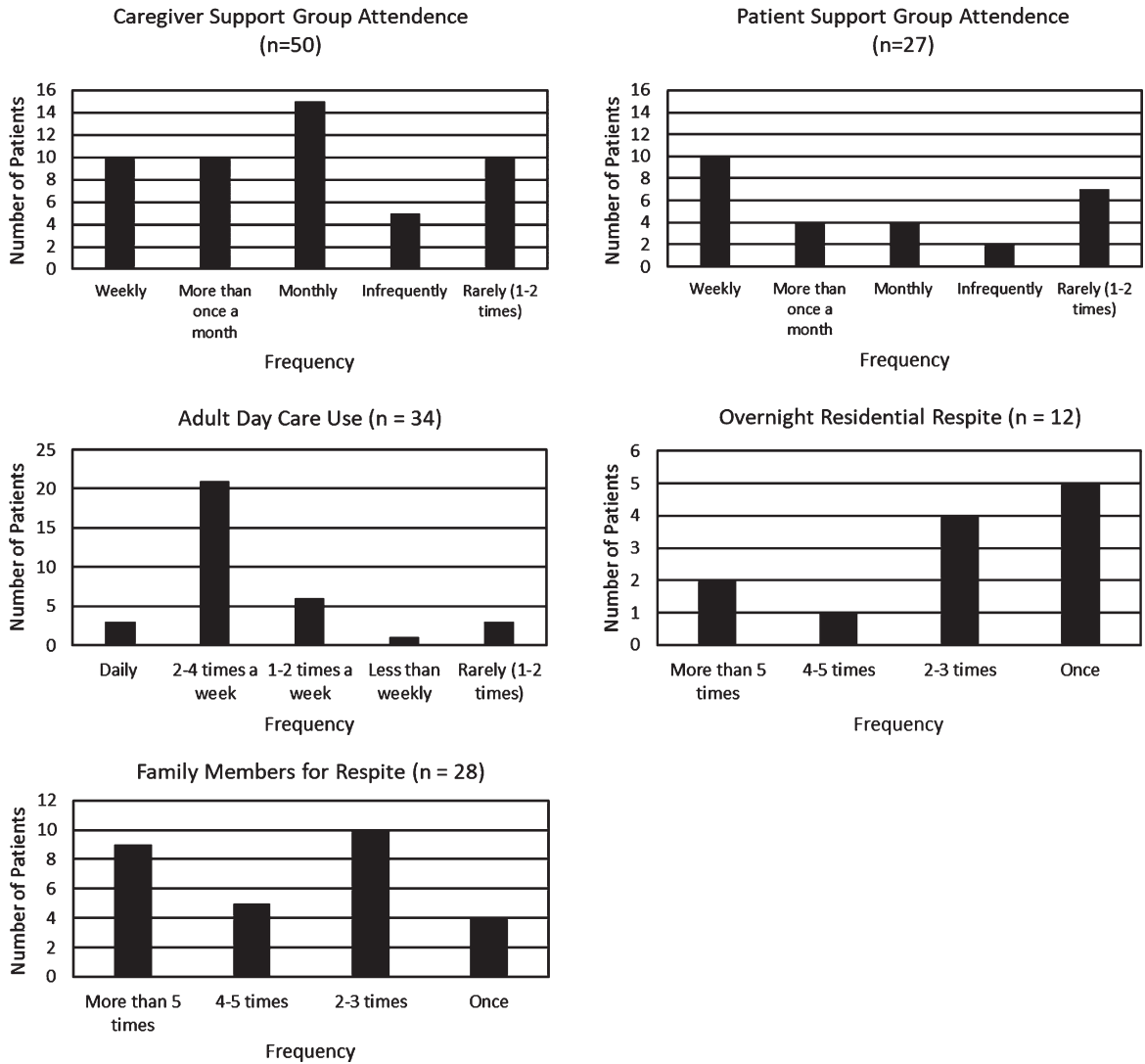


Fig. 1. Frequency of Supportive Care Service Use in the Last Six Months. Note: Missing frequency data for Overnight Residential Respite (n = 1) and Family Members for Respite (n = 2).

Table 3
Hurdle Regression

Variable	Service used				Times used service			
	OR	z	p > z	95% CI	IRR	z	p > z	95% CI
Patient gender (female)	0.74	1.64	0.101	0.51, 1.06	1.39	2.02	0.043	1.01, 1.90
Caregiver group (spouse as base)								
Other family relative	1.31	1.09	0.275	0.80, 2.15	0.99	0.03	0.980	0.47, 2.08
Other caregiver	0.54	0.85	0.395	0.13, 2.25	0.28	94.01	<0.001	0.27, 0.28
Age of patient (current)	1.00	0.17	0.865	0.96, 1.05	0.99	7.58	<0.001	0.99, 0.99
Age of patient at symptom onset	0.98	0.53	0.596	0.92, 1.05	1.04	2.87	0.004	1.01, 1.06
Education (years)	1.06	2.39	0.017	1.01, 1.12	1.08	10.79	<0.001	1.07, 1.10
MMSE total score	0.95	2.93	0.003	0.92, 0.98	0.99	0.16	0.873	0.93, 1.07
BRDRS total score	1.06	2.97	0.003	1.02, 1.11	1.11	0.82	0.415	0.87, 1.42
Number of medications	1.02	3.22	0.001	1.01, 1.04	1.04	0.86	0.388	0.95, 1.14
Number of co-morbid illnesses	1.14	2.65	0.008	1.03, 1.26	1.19	0.99	0.320	0.84, 1.68

OR, odds ratio; IRR, incident rate ratio; MMSE, Mini-Mental State Examination; BRDRS, Blessed Roth Dementia Rating Scale. Cluster-robust standard errors for study site were implemented.

medical conditions (OR = 1.24, $p < 0.001$) (Supplementary Table 2).

Progression of illness and service use frequency

As a secondary analysis, we investigated the relationship between caregivers' perceived progression of the patients' condition and service use frequency. No significant associations emerged between service use frequency and caregivers' perceived change in the patients' condition over both 1 and 6-month time frames (Spearman's $\rho = 0.01$, $p = 0.915$ and Spearman's $\rho = -0.09$, $p = 0.442$, respectively).

While the majority of all SCS users indicated that they received either all or most of the services they needed, 23% indicated that their service needs were not met for one or more services. The breakdown of service insufficiency by SCS type is as follows: caregiver support group (20%), patient support group (30%), adult day care (9%), night respite (8%), and family for respite (13%). A lack of time ($n = 7$) and "other" reasons ($n = 12$) including schedule conflicts, accessibility to services, patient stress/apprehension, service quality, and wrong type of service for patients' needs were most frequently cited as reasons for not receiving enough services. Financial concerns ($n = 5$) and difficulty locating resources ($n = 2$) were less frequently indicated. Transportation difficulty was not specifically selected as a reason for not receiving enough services.

DISCUSSION

This study investigated the prevalence of SCS use and identified factors associated with, and barriers to service use. The current results, while novel in assessing both factors associated with SCS use and SCS frequency, are consistent with previous research on the prevalence of service use. Forty percent of our sample used at least one supportive care service in the six months prior to enrollment in the study. This is in line with the findings of another study with a data collection period similar to ours [29], though lower than the 65.1% of caregivers accessing one or more service in an Australian study [30].

Table 2 shows that, with the exception of family for respite, there was a trend toward higher use of all types of services at the urban site. Caregiver support groups had the most reported use and night respite the least, both overall and at the two study sites (Table 2). This may be due in part to the fact that both study locations offered no-cost on-site care-

giver support groups, making it likely that caregivers would have knowledge of the service through flyers and/or discussions with center staff and that access to this service would be available to all caregivers regardless of their financial means. Caregiver support groups are also widely available at low or no-cost in other off-site locations. In contrast, overnight residential respite care is more expensive and not as easily accessible to all patients. While Veteran patients at Site A had access to a Veterans Affairs overnight residential respite facility close by, patients at Site B did not. This may account for the higher reported use of this service at Site A.

The present findings indicate that more impaired cognition, higher educational achievement, greater impairment in activities of daily living, increased medication use, and more comorbid medical conditions increased the likelihood that services would be used. These findings are similar to those of Scalmana et al. [18], who found that patients with more than five years of education, one or more comorbidities, and severe or moderate dementia had a higher probability of utilizing services. When we examined patient and caregiver-recipient services separately, we found similar patterns of associations to those found with overall service use with regards to MMSE, education, and the number of medications the patient was taking. However, notable differences between the two groups included increased odds of caregiver-recipient service use (caregiver support groups, night respite, and family for respite) for caregivers of male patients and patients with more functional impairment and increased odds of using patient-recipient services (adult day care and patient support groups) for patients with more co-morbid medical conditions.

With regard to frequency of service use, a mostly different set of factors emerged such that younger age, female gender, more education, older age of AD onset, and being cared for by a spouse or other relative were associated with more frequent service use. We speculate that caregivers of younger patients may be more proactive in seeking and obtaining assistance for newly diagnosed patients, in part because of the increase in availability of information and the reduced stigma associated with receiving help because of advancements in awareness and understanding of neurodegenerative diseases. Additionally, this group may be more likely to be offered services and their accessibility to services may be easier. Patients with older ages of AD onset may have had greater disease severity or other health limitations not present in patients with younger ages of onset, thus

requiring more assistance. Regrettably, the Activities Questionnaire did not assess for the use of paid caregivers. It is possible that patients with non-relative caregivers for this study might have received in-home care from a paid caregiver at a higher rate than those with spouses or other family members for caregivers, thus explaining the increased service use frequency among patients with related caregivers.

Our results may suggest that some characteristics associated with a greater need for services (i.e., more illnesses, greater cognitive, and functional impairment) prompt the initial use of services, while those characteristics associated with greater access to more resources (younger patients and those cared for by family members) may facilitate ongoing SCS use. These findings help illustrate characteristics of patients who may need assistance in gaining regular access to appropriate services (i.e., those who have less educational achievement, are older, male, and who present with non-family member caregivers).

A subset of service users (23%) indicated that they did not receive enough services for one or more SCS. A lack of time and “other” reasons as a category were the most frequently selected reasons for not receiving enough services. Surprisingly, transportation difficulties did not appear to impede service use. Further investigation into barriers of regular service use and ways that services could be better tailored to the needs of patients and caregivers could help facilitate increased service use among individuals who have a critical need for, but a low likelihood of using services.

It is notable that the accessibility to some SCS has evolved since the data collection period. Remote services, such as counseling and support groups, are available by phone or video conferencing technology and are growing in availability. Younger caregivers, in particular, may be more amenable to using this type of service.

It is also worth mentioning several distinctions between the study sites that could have contributed to differences in patient characteristics. As previously discussed, Site A is located at a VA hospital and is also near a prestigious university. This could explain the higher percentage of male patients (approximately 30% of patients evaluated at Site A are Veterans and are often male) and higher educational achievement at Site A. Also, the difference in co-morbid medical conditions between sites may not necessarily mean that urban site patients are less healthy. It is possible that these patients may have had access to more

medical care, and thus reported more diagnosed co-medical conditions.

There were several limitations to this study. Most importantly, socio-economic status (SES), patient and caregiver employment status, costs of individual SCS, and the use of paid caregiver services were not collected at the time of survey deployment, thus limiting the ability to ascertain whether or not these factors played a role in service use. While respondents could indicate “financial concerns” as a reason for not receiving enough services, we recommend that future use of the Activity Questionnaire include questions asking for overall barriers to initiating use of SCS. Despite our inability to determine SES from this retrospective dataset, the fact that patient educational background (which may serve as a proxy for SES) [31] was positively associated with SCS usage indirectly suggests that financial limitations may have played a role in patient and/or family ability to use services. Additional information on caregiver age and education would similarly assist in clarifying the characteristics of caregivers seeking services for a person with AD. Finally, it would be beneficial to examine “lack of time” as a reason for not receiving enough services in more detail to gain more specific knowledge about the constraints faced by patients and caregivers. The conclusions of this study should be viewed cautiously given that the initiation and continuation of SCS use may be related to affordability and other economic factors that were not assessed in the survey form at the time of data collection. The cross-sectional nature of the study design also necessitates caution in the interpretation of the results, as causality cannot be determined. Nonetheless, we feel that the evaluation of this multi-site population into an aggregate utilization metric provides meaningful insights into patterns of SCS that can serve to inform future survey designs as well as mechanisms by which SCS can be targeted to more effectively meet the needs of patients and caregivers.

In summary, the present study investigated the prevalence of and factors associated with SCS use by AD patients and their caregivers. Results indicated that 40% of participants or their caregivers used one or more SCS in the 6 months prior to assessment. Whereas individuals with more impaired cognition, higher levels of educational achievement, lower ability to complete activities of daily living, increased medications use, and more comorbid medical conditions were associated with use of an SCS in the past six months; younger age, female gender, more edu-

cation, older age of AD onset, and being cared for by a spouse or other relative were associated with increased frequency of use. Future research should assess the potential role of caregiver age, education, and socioeconomic status in determining SCS use. Given the projected number of families that will face AD in the coming years, it is critical to make sure that service needs are addressed. With benefits ranging from improved self-care for caregivers to delayed time to placement for patients, it is well worth promoting SCS through the use of targeted outreach strategies early in the disease process. Additional benefits include significant cost savings for families and decreased burden on the healthcare system.

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SUPPLEMENTARY MATERIAL

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