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## Section: Caregivers of the Elderly

Sociological Practice Editors

Elizabeth K. Keech  
*Villanova University*

Robert A. Harris  
*Pennsylvania Department of Aging*

John M. Kelley  
*Villanova University*

Lori F. Gerring  
*Xavier University*

*See next page for additional authors*

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## Section: Caregivers of the Elderly

### **Authors**

Sociological Practice Editors, Elizabeth K. Keech, Robert A. Harris, John M. Kelley, Lori F. Gerring, Christopher P. Peters, Jeffrey Michael Clair, Ferris J. Ritchey, Richard M. Allman, Gary T. Deimling, and Wendy J. Looman

# Pennsylvania's Family Caregiver Support Program: A Demonstration Project

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*Elizabeth K. Keech, Ph.D., R.N., Villanova University*  
*Robert A. Harris, M. Div., Pennsylvania Department of Aging*  
*John M. Kelley, Ph.D., Villanova University*  
*Lori F. Gerring, Ph.D., Xavier University*  
*Christopher P. Peters, Villanova University*

## ABSTRACT

*The physical, emotional, and economic burdens of family caregiving can present a serious threat to the stability and continuity of a caregiving situation. Public policymakers, aware of the high costs of replacing such voluntary efforts with publicly funded institutional care, are becoming more and more concerned about the needs of caregivers and possible intervention strategies to meet those needs.*

*This article begins with a description of Pennsylvania's new policy initiative for caregivers, the Family Caregiver Support Program (FCSP). Following is a discussion of the evaluation of the program's demonstration phase by the Human Organization Science Institute of Villanova University. The evaluation concluded that the FCSP has a significant positive impact on the lives and abilities of caregivers, including the reduction of caregiver stress and burden. The concluding summary of program results seeks to sharpen the reader's interest in the potential benefits of an intervention strategy such as this and suggests a need for additional research for the benefit of those concerned about health care cost containment.*

## Introduction

An informal support system consisting primarily of family caregivers provides the care for approximately eighty percent of older persons in America with long-term care needs (U.S. House of Representatives Select Committee on Aging, 1987). For every one elderly resident in a nursing home, there are two individuals in the community with similar disabilities being cared for by relatives (Shanas, 1979). Furthermore, families have been noted as a critical factor in delaying or preventing the institutionalization of elderly family members (Brody, et al, 1978).

Providing care for an impaired family member is associated with a fair degree of stress, often referred to as "caregiver burden." The closer the bond between the caregiver and the carereceiver, the more stressful the caregiving role (Anthony-Bergstone, et al., 1988; Brody, 1981 and 1985; Brody, et al., 1978; Cantor, 1983; Zarit, et al., 1980). The amount and type of care and the frequency of contact also compound the impact on the caregiver (Horowitz, 1985; Pearson, et al., 1988; Silliman and Sternberg, 1988; Stephens and Christianson, 1986). A caregiver who resides with a carereceiver is especially at risk for increased stress because of the close proximity and because, in many instances, the carereceiver has a high level of disability (Stephens and Christianson, 1986).

According to some estimates, there are already about 4.2 million Americans providing care to an impaired spouse or parent and over half of these are the primary caregiver (Stone and Kemper, 1989). These numbers can be expected to increase significantly in the years ahead as the United States population ages, bringing with it a growing incidence of chronic illness and functional impairment requiring the support of caregivers. In addition, social and economic changes have been identified which may impinge upon caregivers' continued ability to provide such a high level of care to elderly relatives (Treas, 1977; Ward, 1985).

Public policymakers, aware of the high costs of replacing such voluntary efforts with publicly funded institutional care, are becoming more concerned about the needs of caregivers and intervention strategies which may be available to meet those needs (Greene and Coleman, 1990).

This paper begins with a description of Pennsylvania's new policy initiative for caregivers, the Family Caregiver Support Program. This is followed by a discussion of some of the findings from the evaluation of the program's two-and-a-half-year demonstration phase by the Human Organization Science Institute of Villanova University. The concluding summary of program results seeks to sharpen the reader's interest in the

potential benefits of an intervention strategy such as this and suggests a need for additional research for the benefit of those especially concerned about health care cost containment.

### **The Family Caregiver Support Program**

In the mid-1980s, the Pennsylvania Department of Aging clearly recognized the need to provide support for caregivers. A generalized concern that something be done to bolster family support systems had begun to be widely articulated by advocacy organizations, service providers, and departmental staff. This concern grew out of needs perceived at the grass roots level and was supported by a variety of national research studies which showed that, contrary to popular belief, most of the care provided to dependent elderly persons is provided by family members—not by nursing homes or formal agencies.

A nationwide study of family caregiver incentive policies completed for the department (Biegel, et al., 1986) influenced the initial conceptualization of a policy initiative to provide stronger incentives to family members to assume or maintain the role of caregiver to a functionally dependent older relative. An early decision was made to develop a demonstration program which would explore the local coordination of service incentives with financial incentives. It was also decided that, since the state constitution prevented the department from providing cash grants, a reimbursement approach to financial assistance would be tried. This later proved to be important from the perspective of caregiver taxable income. Additional program design utilized valuable input from a focus group of representatives of caregivers on caregiver issues. In 1987, the department initiated the Family Caregiver Support Program (FCSP) as a demonstration project in four sites competitively selected from Pennsylvania's 52 area agencies on aging. The four sites, representing different kinds of communities and geographical areas, were:

*Bucks County Area Agency on Aging, Doylestown, PA*  
*North Central Human Services, Inc., Ridgway, PA*  
 (Cameron, Elk, and McKean Counties)

*Philadelphia Corporation for the Aging, Philadelphia, PA*  
*Southwestern PA Area Agency on Aging, Monessen, PA*  
 (Washington, Fayette, and Greene Counties)

The Family Caregiver Support Program is designed to reduce caregiver burden and reinforce the care being provided to older persons at home. Focusing on the needs of caregivers, the program provides a combination of services and financial assistance to families caring for a functionally dependent older relative who is living with them. The program is currently being implemented throughout the state under recently enacted legislation which slightly expands the client group to include the caregivers of adults of any age with Alzheimer's Disease or other chronic dementia. Locally, the program is administered by Pennsylvania's 52 area agencies on aging.

The basic components of the program are:

- a comprehensive assessment of the needs of the caregiver, the care-receiver, and the caregiving environment;
- benefits counseling;
- caregiver training and education; and
- financial assistance with ongoing caregiving expenses, home modifications, and assistive devices.

Financial assistance is in the form of reimbursement for expenses incurred. Depending upon need, income, and expenditures, caregivers may be reimbursed for up to \$200 per month for services and supplies (e.g., respite care, incontinence supplies, etc.); and up to \$2000 for home modifications and assistive devices. Families with incomes of up to 200 percent of poverty level are eligible for 100 percent of the maximum financial benefit available. As income increases by 20 percent beyond this level, the benefits decrease by 10 percent, until they phase out at 380 percent of poverty level.

The principal goals of the FCSP are:

- To reduce caregiver burden.
- To enable caregivers to provide effective and appropriate care through benefits counseling and caregiver education.
- To empower caregivers, through expense reimbursement, to choose respite care options and other supports as they determine most appropriate.
- To extend the benefits of the FCSP to middle income families through the use of income-related cost sharing.

In two respects, the FCSP design represents a significant departure from traditional social service delivery. First, there is a focus on the family as the client and manager of the older person's care. Second, the program

includes direct reimbursement of caregivers for out-of-pocket expenditures of their own choosing. Social agencies often view clients as people whom they need to "care for" and "cases" which they need to "manage." This conceptualization subtly pervades many aspects of the human service delivery system and may explain why some families do not seek help even when they need it. The department saw this attitude as an obstacle to the successful implementation of an effective caregiver support program. Thus, the FCSP was intentionally designed to reinforce the caregivers' ability to manage the care needed by their relatives.

The department believed that if the program effectively targeted the caregiver, it would be possible to reach a different service population than that currently being reached by other programs for the elderly. The demonstration sites were skeptical about this. They believed that they would not discover many families whose older functionally dependent relative was not already known to the area agency on aging. The "unlearning" was achieved through the persistence of the department, the cooperation of the four demonstration sites and the program experience which eventually showed that a large percentage of the FCSP client families were not previously known to the AAA. Data from the *Final Evaluation Report* indicate that 48.5 percent of the carereceivers in families served during the demonstration were new to the agencies (Kelley, et al., 1990).

The area agency on aging sites also did not initially believe that their County Commissioners or Boards of Directors would allow them to make direct payments to clients. All, however, have been able to implement direct reimbursement procedures using some system of invoicing which provides adequate documentation for agency payments. The integration and local coordination of service and financial program benefits is an essential factor in the FCSP model and contributes to an expansion of local service options for caregivers. It also allows the agencies to work in partnership with caregivers to provide a more holistic approach to family support—making them more capable of looking beyond the needs of the older dependent relative to see other kinds of family intervention needs.

### **Evaluation of the Demonstration**

Villanova University's Human Organization Science Institute was selected from among five bidders as the project evaluator for the FCSP in November 1987. The methodology utilized to evaluate the program was a longitudinal design which included both quantitative and qualitative methods, including

descriptive statistics, process documentation, pre- and post-correlational analysis, and analysis of variance. Significance of correlations was determined at .05 level of significance.

All caregivers participated in a 2-4 hour interview in the caregiver's home. The interview was structured by a standardized multidimensional assessment instrument which contained a mix of scale items, and fixed choice and open-ended questions. The interviews were conducted by case managers in the four demonstration sites. All caregivers remaining in the program long enough were interviewed again at 6-month intervals using the same assessment instrument.

The key study questions discussed in the *Final Evaluation Report* (Kelley, et al., 1990) address the following concerns:

- Social, demographic, and functional characteristics of program participants.
- Discernible differences in caregiver well-being, stress, and ability to function in the caregiving role.
- Facilitators and barriers to program implementation and operation.
- Procedures used by the agencies to manage program funding and cost-sharing responsibilities.
- Family satisfaction with the program's services.

The evaluation study period extended from December 1987 to February 1990. The study was designed to gather data on each enrolled caregiving family for a period of at least six months. Data was collected for initial assessments between December 1987 and August 1989. Data for six-month reassessments were collected until February 1990. Service data were collected for the entire study period. While attrition decreased the number of participating families, a majority of enrolled families (480) were reassessed after six months, and a substantial number (200) were reassessed again after twelve months. A smaller number of families (58) were reassessed for a third time after eighteen months. The data presented in this paper reflect information gathered on each client family at the initial assessment and again at the 6-month reassessment.

### Caregiver/Carereceiver Characteristics

Between December 1987 and August 1989, a total of 833 caregiving families (833 caregivers and 842 carereceivers) were assessed and admitted to the FCSP. The caregivers and their carereceivers were representative of



**TABLE 1**  
**Selected Characteristics of Caregivers and Carereceivers**

Category	Caregiver	Carereceiver
Admissions		
Total	833	842
Carereceivers previously unknown to Area Agency on Aging		48.5 %
Terminations (entire study period)	466	—
Demographics		
Females	74.8%	58.4%
Average Age	62.2 yrs	77.2 yrs
Average Highest Grade Completed	11.0 yrs	9.3 yrs
Employed Full-Time	10.5%	0.0%
Veteran	9.6%	15.5%
Racial Identity		
Asian	0.2%	0.4%
Black	20.8%	20.2%
Hispanic	1.7%	1.8%
White	77.3%	77.7%
Relationships		
Mothers	0.4%	31.2%
Wives	32.7%	17.2%
Daughters	30.6%	0.0%
Fathers	0.0%	5.9%
Husbands	17.7%	32.4%
Sons	5.9%	0.4%
Siblings	3.6%	3.7%
In-Laws	3.6%	3.7%
Other	4.9%	4.9%
Physical Health		
Average Physical Health Problems	2.1	3.5
Average Medications	2.2	4.7
Average Visits to Health Care		
Professional (in prior six months)	3.7	6.8
Average Hospitalizations (in prior six months)	0.2	0.9
Continent of Bladder	—	57.7%
Continent of Bowel	—	69.0%
Average ADL Needs (of 8 possible)	0.1	5.3
Average IADL Needs (of 12 possible)	1.6	10.6

*(continued on next page)*

**TABLE 1 (cont.)**  
Selected Characteristics of Caregivers and Carereceivers

Category	Caregiver	Carereceiver
<b>Mental Health</b>		
Average Mental Status Quotient (MSQ) Score (of 9 possible)	—	4.2
Carereceivers with mild to severe cognitive impairment	—	31.9%
Carereceivers unable to respond to MSQ cognitive ability test	—	23.5%
Average Zarit Score (of 88 possible)	32.9	—
Caregiver participation in Support Group	9.6%	—

the national profile of caregivers, in that the majority were female, predominantly wives and daughters (see Table 1). However, some men did act as caregivers (25 percent) and at one rural demonstration site thirty-seven percent of the caregivers were male. The percentage of caregivers working full-time was only 10 percent but an additional 12 percent stated that they left employment to become a caregiver.

The participants in the demonstration program represented a previously underserved population group, characterized by ill health, moderate stress, and long hours of care provision with little opportunity for relaxation or respite. They were financially needy, having limited incomes and high expenses. Caregivers consistently reported that they were never out of their caregiving roles. Caregivers were found, on average, to be active in the role of caregiver for eighteen hours a day, and many stated that they were required to be with the carereceiver twenty-four hours a day. The fear that these caregivers are stressed and nearing a time when they will no longer be able to offer care for their dependent relative is legitimate.

Initial attrition rates demonstrate the frailty of the carereceiver population. Of the 466 terminations, 45 percent were due to carereceiver death and 23 percent were as a result of nursing home placement. The average time in the program for families whose service was terminated was just over six months.

### Caregiver Burden

One of the primary objectives of the FCSP is to provide support to the caregiving situation, thereby reducing the caregivers' burden. The evaluators

considered changes in caregiver burden to be one of the major measurements of program impact.

Care managers administered a validated twenty-two question survey known as the Zarit Caregiver Burden Scale (Zarit, et al., 1980). This scale uses a five point (0-4) rating system to measure caregiver burden and stress, with a possible total score of 88. Overall, caregiver Zarit scores were well within the mild-to-moderate range (mean = 32.9), with many caregivers (45.7 percent) falling within this rating. Caregivers scoring within the little-to-no-burden range (24.1 percent) and the moderate-to-severe range (24.5 percent) were roughly equivalent. Few caregivers scored within the severe burden range (5.7 percent).

### Caregiving Tasks

Twenty-two caregiving tasks were reviewed. Some were not applicable to all caregiving situations. Caregivers, for the most part, tended to perform tasks themselves (mean = 9.7 tasks) rather than supervising the activities of the carereceiver (mean = 3.1 tasks). The large number of tasks being performed also indicated the level of carereceiver need for care.(See Table 2.)

These same twenty-two tasks were reviewed to identify three other factors of caregiving: those items the caregivers felt cause stress, those items the caregivers wanted help with, and those items the caregivers preferred to do themselves. Maintaining the carereceivers' personal hygiene was reported most frequently as the task causing stress (25.8 percent) and as the task caregivers wanted help with (31.1 percent). Similar consistency was found in the area of providing constant supervision and companionship, with nearly one-quarter of caregivers finding this stressful (22.4 percent) and wanting help with the task (22.2 percent). Assisting with ambulation or lifting the carereceiver caused stress for approximately the same number (19.3 percent) as those wanting help (16.5 percent) with the task. Tending incontinence or assisting with toileting found similarity between stress (13.1 percent) and wanting help (10.8 percent). The relative ranking of tasks causing stress and tasks where help was wanted was identical for these four tasks. In terms of the tasks caregivers preferred to do themselves, performing other caregiving tasks (29.4 percent), providing basic medical care (20.7 percent), and maintaining nutrition (19.5 percent) ranked first, second, and third, respectively. It should be noted that some caregivers preferred to perform the tasks of maintaining personal hygiene (12.8 percent) and providing the necessary supervision and companionship (8.6 percent).

**TABLE 2**  
Description of Caregiver Needs by Site

		n = 833
<u>Caregiver Activity</u>		
Mean Items Caregiver Does		9.7
Mean Items Caregiver Supervises		3.1
<u>Item Causing Caregiver Stress</u>		<u>Responses *</u>
Personal Hygiene		454
Toileting/Incontinence		231
Ambulation/Lifting		339
Medical Care		49
Nutrition		117
Supervision/Companionship		393
Other		172
<u>Items Primary Caregiver Wants Help With</u>		
Personal Hygiene		593
Toileting/Incontinence		206
Ambulation/Lifting		314
Medical Care		40
Nutrition		104
Supervision/Companionship		423
Other		209

\*Caregivers were able to respond to more than one item.

### Caregiving Supports

While caregivers performed a variety of tasks and provided the vast majority of care required by their dependents, most were not entirely alone in their caregiving endeavors at the time of assessment. Informal support, provided without compensation by other family members, friends, and neighbors, was evident in the majority of homes, with only a few caregivers (9.2 percent) reporting no such support. Overall, most caregiving families received informal support from several sources (mean = 2.4 informal supports), and over one-third (38.5 percent) reported support from at least three informal sources.

In addition to informal supports, families availed themselves of the formal support network. Formal supports are classified as persons providing care in exchange for compensation, and are typically available through an

agency or organization. While some use of formal supports was reported, it was at a much lower rate than the use of informal supports, with most families identifying only one formal support (mean = 1.2). Almost one-third of all families (31.9 percent) reported having no formal supports prior to admission into the FCSP.

When asked to identify the most important form of support, most caregivers cited the informal sources (44.6 percent). Formal supports were also identified with substantial frequency (34.0 percent), indicating that support, whatever the source, was considered to be important by the caregivers. Over one-tenth of the caregivers (11.7 percent) reported having no important supports, while slightly less (9.7 percent) identified the combination of informal and formal supports as being important.

### **Service Delivery and Utilization**

Services of the FCSP fit into one of five basic categories. *Core services* include the assessment process (initial and subsequent), ongoing care management, benefits counseling, and caregiver education. These services are provided directly by the FCSP at no cost to the caregiver. Caregiver education is a partial exception, since it may, in some cases, be a purchased service also. The other services of the FCSP are provided as a result of caregiver selection and use of the financial reimbursement funds for respite care and other supportive services. These services include: *In-Home Services* (household management, in-home personal care, and general respite care); *Out-of-Home Services* (adult day care and overnight respite care); *Consumable Supplies* (such as incontinence supplies); and *Assistive Devices and Home Modifications*.

Each site was asked to submit a monthly report of services delivered. This report included information on units of service, amounts of reimbursement, and caregiver/program cost-sharing ratios. These data helped to provide some indication of the patterns and costs of service utilization. Table 3 shows the percentage of all enrolled families who used the various services. It should be noted, however, that the apparent low utilization of adult day care and overnight respite care are more related to the limited availability of these services than to caregiver choice. By contrast, in Philadelphia and Bucks County, where adult day care is more accessible, 10.5 percent and 15.4 percent, respectively, of enrolled families used this service.

**TABLE 3**  
Families Receiving Services by Type

Category	Percent of Total (n = 833)
<b>Core Services Rendered</b>	
Assessments	97.1
Consultant Assessments	9.9
Benefits Counseling	74.2
Training/Education	25.6
Family Counseling	9.8
<b>In-Home Services</b>	
Household Management	26.4
In-Home Personal Care	58.1
<b>Out-of-Home Services</b>	
Adult Day Care	7.9
Overnight Respite Care	4.6
<b>Assistive Devices and Home Modifications</b>	
Assistive Devices	20.2
Home Modifications	15.4
Consumable Supplies	34.2

Of the more than eight hundred thousand dollars (\$804,874) spent by the program to reimburse caregivers for the purchase of such services during the total study period (December 1987 to February 1990), the majority (52.5 percent) went toward the purchase of In-Home Personal Care. Considerably less was spent on Household Management (15.4 percent), Home Modifications (11.0 percent), Consumable Supplies (8.2 percent), Adult Day Care (5.9 percent), Assistive Devices (3.6 percent), Overnight Respite (3.2 percent), and Other Services (0.3 percent). Caregiving families spent over one hundred and fifty thousand dollars (\$155,655) in addition to the amount reimbursed by the program, representing less than one-fifth of the total dollars spent (16.2 percent of \$960,529).

### **Annualized Program Costs**

Although the FCSP demonstration contracts officially ended on June 30, 1990, the data collected for the evaluation study only cover the provision of services until February 1990. Consequently, some final cost data was not

**TABLE 4**  
Family Cost-Sharing Data

Category	Cost	Percent of Total Costs	Percent of Costs Paid by Families
Total Reported Costs of			
Purchased Services	\$960,529	100.0	
Total Paid by Families	\$155,655	16.2	
Total Paid by Program	\$804,814	83.8	
In-Home Household Management		15.4	5.7
In-Home Personal Care		52.5	19.2
Out-of-Home Adult Day Care		5.9	21.2
Out-of-Home Overnight Respite Care		3.2	24.8
Assistive Devices		3.6	7.3
Home Modifications		11.0	9.6
Consumable Supplies		8.2	18.0

available to the evaluators for discussion in the evaluation report. Furthermore, various start-up delays prevented optimum caseload levels from being reached until the final contract year. Thus, total program expenditures for the last twelve months of the demonstration (\$1.5 million) were even a little higher than the expenditures during the entire two-year period covered by the evaluation data. The data from this one full year of stabilized and consistent service levels provides us with the best annualized cost data on the demonstration program. The following observations on the final twelve months are noteworthy:

- Total contract expenditures .....\$1,519,233  
(7/1/89 - 6/30/90)
- Total caregiver reimbursements ..... \$882,160
  - 83 percent for ongoing expenses (respite, etc.) ... \$732,680
  - 17 percent for home modifications and assistive devices..... \$149,480
- Unduplicated number of families served  
(7/1/89 - 6/30/90).....1,006
- Average total cost per family.....\$1,510
- Average active caseload (est.)..... 675  
(based on approx. attrition rate of 33 percent/yr.)
- Average total cost per caseload slot (est.).....\$2,250

## **Local Program Variations**

The qualitative review of the FCSP's local operation established the adaptability of the basic program model to local needs and available service resources. Even though there was extensive inter-agency sharing through frequent networking meetings during the demonstration, the four participating sites developed local programs with some significant differences.

Each site focused its efforts differently on the various aspects and components of the FCSP. One placed a heavy emphasis on benefits counseling. Another stressed home modifications. A third expanded agency core services to provide, at no cost to caregivers, coping skills counseling for all interested client families. Care management staff was structured and utilized differently in all four sites.

All four sites devoted substantial attention to the development of their financial reimbursement system and caregiver cost-sharing protocols. One site instituted a voucher system for the purchase of respite care and other services. In all cases, the sites were able to produce systems that provided the necessary accountability for payments to caregivers without imposing a burden or extensive paperwork requirements on them.

Of the program model variations developed in the four local sites, none emerged as more appropriate or successful than another. This seems to underscore the importance of allowing local agencies flexibility in the local adaptation and implementation of programs they will be expected to operate. It also carries positive implications for the replicability of the FCSP in other communities.

## **Correlation Analysis of FCSP Participation**

Starting with the hypothesis that a low sense of burden, coupled with low-risk behaviors and involvement in activities of interest outside of the home, support continued caregiver functioning, the evaluators used three measures to determine change in caregiver stress and functioning. The first measure was the validated Zarit Scale of Caregiver Burden. This twenty-two item rating scale measured caretakers' perceptions of personal stress and burden using both behavioral and subjective ratings. The evaluators created two additional measures, the Caregiver Well-Being Scale and the Caregiver Social Functioning Scale. The Well-Being Scale measured a series of risk behaviors, such as sleeping patterns, eating patterns, medication misuse, alcohol misuse, and sense of satisfaction. The Social



Functioning Scale assessed the caregivers' involvement in community, social, and personal activities. Each of the three scales provided a numeric score. For the Zarit Scale, a low score indicated a low sense of burden while a high score indicated a high sense of burden. For the Caregiver Well-Being Scale, higher scores indicated healthier behavior. Higher scores on the Social Functioning Scale indicated greater caregiver involvement in activities outside of the home.

The evaluators found significant statistical correlations between the three scales. The Zarit Scale was significantly and negatively related to both the Well-Being and Social Functioning Scales. This indicated that higher stress levels, as measured by the Zarit scale, were statistically related to unhealthier behaviors and limited social activity, as measured by the Well-Being and Social Functioning Scales, respectively.

The evaluators further applied the three different scale scores to a series of correlation tests, seeking to confirm the relationship of: ten variables of caregiver status, such as age, education, physical and emotional health, and ADL and IADL needs; six variables of carereceiver status, such as age, mental competence, ADL and IADL needs, and independence; and ten variables of family status, such as years in a relationship between caregiver and carereceiver, caregiver activities of caregiving, level of paid and unpaid external support, income, and caregiving expenses.

The correlation analyses were performed using the initial assessment scores of the three scales. The Zarit Scale proved to have significant relationships with sixteen of the selected variables. The Social Functioning Scale also proved to be significantly associated with sixteen variables, eleven overlapping with the Zarit Scale. The Well-Being Scale showed twelve significant relationships with the selected variables, six overlapping with both the Zarit and the Social Functioning Scales. The fact that the three scales were statistically related to each other, yet produced different correlation values with the twenty-six caregiving variables, indicated that each scale was identifying different, and significant, aspects of caregiver burden and/or satisfaction.

On a pre-post analysis, changes in perceived caregiver burden, caregiver social functioning, and caregiver well-being were examined by readministering the three interviews (Zarit, Social Functioning, and Well-Being) at six months, twelve months, and eighteen months following the initial assessment. The changes in scores from the initial assessment to subsequent assessments were calculated. These analyses showed that there were significant decreases in the Zarit Scale of Caregiver Burden matched by significant increases in the Caregiver Social Functioning and Well-Being Scales.

**TABLE 5**  
Matched Pair Analysis

Correlation of Caregiver Variables with Initial Assessment Score			
	Score		
	6 months (n=480)	12 months (200)	18 months (58)
Zarit Scores	-4.14*	-4.03*	-4.66*
Caregiver Social Functioning Scale	3.50*	.66	2.19
Caregiver Well-Being	3.40*	3.50*	2.78*

\* p=.05

To determine which of the twenty-six variables had significant relationships with changes in caregiver burden, correlation tests were run using the change in stress level (Zarit) and those variables determined to significantly correlate at the point of initial assessment. Table 6 shows the relationship between the selected variables and the changes in stress at the point of the first reassessments (6th month review). For the combined group, the following results emerge:

- As carereceiver Instrumental Activities of Daily Living (IADL) needs increased, caregiver stress likewise increased and caregiver social functioning decreased;
- As the number of items the caregiver did increased, caregiver social functioning decreased;
- As the number of hours the caregiver was required to provide care increased, social functioning decreased.
- As the family's purchases of caregiving services increased, stress decreased; and,
- As caregiver personal time, visiting activity and hobby activity increased, stress decreased and social functioning increased.

**TABLE 6**  
 Correlations between Change in Zarit Scale and Change in Selected Variables at Six Months (Significance Determined at .05)(n = 492)

	<u>Zarit</u>	
	Corr.	Sig
Caregiver IADL Needs	.021	
Carereceiver IADL Needs	.117	Yes
Number of Items Caregiver Does	.059	
Number of Items Caregiver Supervises	-.060	
Caregiver Hours Caregiving Per Day	.125	
Number of Formal (Paid) Caregiver Supports	.001	
Number of Informal (Unpaid) Caregiver Supports	.026	
Monthly Cost of Caregiving Services (To Family)	-.162	Yes
Monthly Cost of Caregiving Supplies (To Family)	-.014	
Caregiver Personal Time Activity	-.178	Yes
Caregiver Visiting Activity	-.139	Yes
Caregiver Hobby Activity	-.096	Yes

These findings suggest that a caregiver's sense of demands on his or her time was directly related to his or her sense of stress and social isolation. Also, the appropriate intervention of purchased services (with cost-sharing by the FCSP program) to provide respite contributed to an increase of personal time and a reduction of stress, despite the additional costs to caregivers.

Table 7 displays the results of correlation tests of the connection between service variables and selected variables of caregiver need and activity. Tests include all services combined and each of the service categories (In-Home, Out-of-Home, Assistive Devices and Home Modifications, and Consumable Supplies).

**TABLE 7**  
**Correlations between Service Variables and Change in Selected Variables**  
**Initial Assessment versus First Reassessment (6 months)**  
**All Services Combined**  
**(Significance Determined at .05)**  
**(n = 488)**

Selected Variable	Frequency of <u>Service events</u>		# of <u>Hours</u>		Program <u>Expenses</u>	
	Corr.	Sig.	Corr.	Sig.	Corr.	Sig.
CG Zarit Score	.085	—	-.153	Yes	.131	Yes
CG Social Functioning Scale	.103	—	.070	—	.023	—
CG IADL Needs	.142	Yes	.244	Yes	.157	Yes
CR IADL Needs	-.167	—	-.057	—	-.096	Yes
# of Items						
CG supervises	.120	Yes	.212	Yes	.227	Yes
CG Personal Time Activities	.076	—	.125	Yes	.097	Yes
CG Visiting Activity	.114	Yes	.178	Yes	.158	Yes
CG Hobby Activity	.134	Yes	.134	Yes	.126	Yes

CG = Caregiver  
 CR = Carereceiver

These correlation analyses indicate:

- As the level of service hours and program expenses increased, the level of stress decreased.
- As the personal functional needs of the caregiver increased, more services were provided.
- As the level of service events, service hours, and program expenditures increased, the number of caregiving activities the caregiver was able to supervise (as opposed to do) increased.
- As the level of service hours and program expenses increased, the amount of reported caregiver personal time increased.
- As service events, service hours, program expenses, and the number of different services increased, reported caregiver visiting increased.
- As service events, service hours, program expenditures, and family expenses increased, caregiver hobby activity increased.

## Program Results

The results of the FCSP Demonstration can be summarized as follows:

(1) The program reached a highly needy population. Carereceivers had an average of 3.5 distinct physical health problems; took an average of 4.7 different medications; and in over one-third of the cases were not continent of bowel or bladder. At least one-third of the carereceivers were cognitively impaired. The average age of caregivers in the program was 62. Over half of the 833 families participating in the demonstration reported an annual income of \$17,250 or less. Average household size was 2.6.

(2) The program was an effective resource for caregivers. Statistical correlations indicate a reduction in caregiver stress, an increase in caregiver well-being, and an increase in available time for personal activities. Also, over 90 percent of all respondents to a satisfaction questionnaire judged the program as having made positive differences in their lives, lessened their stress, and made it easier for them to care for their relatives.

(*Final Evaluation Report* data covering a two-year period, January 1, 1988 to December 31, 1989.)

(3) Given the amounts available for caregiver reimbursement, overall costs were lower than many anticipated. Data from the last full (12-month) contract year, ending 6/30/90, indicated the following: average total program cost per family = \$1510; average family reimbursements = \$877; average total cost per caseload slot = \$2250; average reimbursements per caseload slot = \$1307.

*Note:* "Caseload slot" is used to identify one unit of the average daily caseload over a 12-month period. The average cost of a "caseload slot" is determined by dividing the total program expenditures reported by the average daily caseload. One "caseload slot" may, with attrition, be used to serve more than one family in a 12-month period. Due to fixed funding levels, agencies may control expenditures by projecting the number of caseload slots which available funding will sustain. Thus, the importance of distinguishing between the average annual cost of services to one family and the average annual cost of funding one caseload slot.

What the demonstration did not establish is a body of evidence related to its cost effectiveness. It may be presumed that providing support to family caregivers reduces stress-related health problems and avoids or delays the placement of older persons in nursing homes or other institutions. Proof of this, however, would require a sophisticated research design involving a longitudinal study of experimental and control groups. The department may

undertake such an evaluation in the future, but in the meantime, the merits of the program must be couched in humanistic terms. Further data would be needed to demonstrate program effectiveness to those who are principally concerned about cost containment.

The FCSP has enabled the department to get much-needed help to a new group of clients who traditionally have not taken advantage of formal services for impaired older persons. Many of the caregivers served have apparently operated from the assumption that, since they take care of their older relatives, they don't need to depend on formal services to provide that care. Often, they have not absorbed the full depth of their own needs. In the words of the Director of one of the AAA Demonstration sites, "We are discovering some very heroic people through this program."

Because the program is directed to the needs of caregivers, many of these people seem more open to seeking help for themselves than they were to looking for an agency to provide care to their relatives. Because of this achievement, we are also able to provide official acknowledgment of the important role dedicated family caregivers are playing in the provision of long-term care services to impaired older persons.

The FCSP proved to be a viable and beneficial program. It clearly met its primary objective to reduce the stress encountered by caregivers as they provide for the daily needs of their aging, dependent relatives. It demonstrated the viability of new methods of service delivery, the provision of financial assistance, and the ability to successfully empower clients.

The most substantial measure of FCSP impact was on the caregivers' reported levels of stress and burden. In studying the relationship between services delivered and changes in stress, there was indeed a direct and statistically significant relationship between the services caregivers received, their use of reimbursement funds, and changes in their levels of stress. As services and use of reimbursement funds increased, stress decreased. The evaluators can state with confidence that the program achieved its objective of having a beneficial impact on the lives and functioning of the caregivers. Within the limits of the evaluation, no one service type emerged as being more important than others in terms of reducing stress. It appears to be the availability of the program and the combined array of services, in total, that produces a positive impact.

## Note

Pennsylvania's Family Caregiver Support Program has now been fully implemented throughout the state through the 52 Area Agencies on Aging. The Program received an appro-

priation of \$8.5 million for State Fiscal Year 1991-92, which ended on June 30, 1992. Of that amount, approximately \$7 million was spent. The appropriation for State Fiscal Year 1992-93 was \$8.55 million. The average cost per family served during 1991-92 was \$1550 and the average cost per caseload slot was \$2500. The program is currently funding approximately 3400 caseload slots which provide services to approximately 5500 families each year. Legislation enacted late in 1990 extended the benefits of the Program to the caregivers of younger adults (under age 60) with chronic dementia, such as Alzheimer's Disease. The impact of that expansion is still being studied.

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# Satisfaction with Medical Encounters Among Caregivers of Geriatric Outpatients\*

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*Jeffrey Michael Clair, University of Alabama at Birmingham  
Ferris J. Ritchey, University of Alabama at Birmingham  
Richard M. Allman, University of Alabama at Birmingham*

## ABSTRACT

*Caregivers' experiences and satisfaction with physicians and medical services provided to geriatric patients are reported. An outstanding predictor of satisfaction with physician communication and overall patient care was the extent to which caregivers were experiencing role strain. Other significant predictors included caregiver knowledge of clinic and social support services provided to patients. The data suggest that, irrespective of the quality of clinic services and physician communication style, some caregivers will be dissatisfied because their encounter is mediated by the stress of activities separate from the medical encounter. We assert the importance of specialized geriatric services and argue that if these services are not in place, caregiver satisfaction with the overall medical encounter will likely be much lower.*

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This work fits within the broader context of studies focusing on the elderly patient-physician relationship (Greene, et al., 1987; Haug, 1986, 1987; Zola, 1986), and extends attention to the caregiver-physician relationship. Caregivers are dynamic participants in the patient care process (Jecker, 1990; Kapp, 1991). To examine only the patient-physician relationship ignores much of what is known about medical care services and utilization today, specifically, the fact that over two-thirds of geriatric outpatients are accompanied to the health care facility by a caregiver (Beisicker, 1991; Clair and Allman, 1993). These caregivers provide their own perspective about the patients' medical history and current health problems (Coe and Prendergast, 1985; Jecker, 1990). As the patient's health diminishes, the relationship between caregiver and physician intensifies. Given the pivotal role caregivers often play in the medical care of geriatric patients, it is important to explore the caregiver-physician relationship (Glaser, et al., 1990; Haley, et al., 1992).

The purpose of this paper is to provide data which increase our understanding of family caregivers' experiences, and their satisfaction with the medical services provided and the physicians involved in diagnosing and managing the geriatric patient's health problems. Whether or not caregivers feel integrated in the health care process through their communications with physicians is documented. This integration entails that physicians consider caregivers an important source of patient information, adequately attend to their questions, communicate in a clear manner, and spend enough time with them. Whether doctors provide sufficient time, information, and psychosocial support to caregivers should account for varying degrees of satisfaction with medical services and provider communication. Addressing these issues, most of which parallel the many problems identified by caregivers during counseling, is the focus of this paper (See Smith, et al., 1991).

### **The Caregiver-Physician Relationship**

Many researchers stress the clinical and theoretical importance of effective communication in medical encounters (Inui, et al., 1982; Mishler, 1984; Waitzkin, 1984, 1985, 1989, 1991; Woolley et al., 1978). Both empirical data and clinical experience suggest that there are important ways that physicians can maintain and enhance the health and well-being of patients, as well as family caregivers, by fostering "mutuality" through a triadic relationship (Beisecker, 1988; Clair, 1990a; Silliman, 1989).

Geriatric patients usually have a complex array of interacting biomedical, psychosocial, and functional disabilities (Silliman, 1989, 1993). Caregivers play a substantial role in assisting patients in daily activities (Radecki et al., 1988a, 1988b). In addition to the physical disabilities associated with age-related co-morbidities, many older patients have cognitive impairment that compromises their ability to exercise judgment and report symptoms and experiences. Caregivers have knowledge of the patient's physical, social, cognitive, and financial well-being, and bring this information to the medical encounter. This factor necessitates that physicians extend their learning possibilities and information-giving practices to caregivers (Haley, et al., 1992).

Research on geriatric encounters typically focuses on the many problems that exist between doctors and their geriatric patients, especially difficulties of patient communication (Adelman and Albert, 1987; Baker, 1984; Beland and Maheux, 1990; Haug and Ory, 1987; Greene, et al., 1986). Other studies call attention to problems with the elderly person's capacity for self care (Haug, 1986; Zola, 1986). Waitzkin (1991) notes that some of the most interesting and important features of research on geriatric medical encounters involve concerns about matters that appear marginal or peripheral to the technical goals of clinical medicine. He found that elderly patients' personal troubles included social isolation, financial insecurity, loss of community and material possessions, death of family members, and retirement from work. Physicians often responded to such social psychological problems by cutting off any discussion about social context and reemphasizing technical matters. At best, the current literature only implicitly addresses the pivotal role caregivers play in this relationship.

### **Geriatric Outpatient Care**

In view of the search for effective techniques to improve care for the complex and interactive health problems of the elderly, geriatric outpatient services represent promising approaches. Research on geriatric clinics documents their effectiveness in diagnosing physical and psychosocial functioning (Applegate, et al., 1991; Epstein et al., 1990; McVey et al., 1989; Rubenstein et al., 1984; Williams et al., 1987). However, it is clearly not enough for a geriatric assessment simply to diagnose physical and psychosocial functional capacities. Improved care requires input from caregivers and the results of patient assessments must be transmitted to both the patient and the caregiver (Rubenstein, 1987).

Findings from 30 years of gerontological research suggest that families have provided and will continue to provide substantial care for their aged (Borgatta and Montgomery, 1987; Brody, 1985; Clair, 1990b; Maddox and Glass, 1989; Olesen, 1989). For many patients, family caregivers are the critical link in enhancing the continuity of care, providing direct physical care, socio-emotional and financial support, and interfacing with physicians and the formal health care system as case managers (Clair, 1990a; Horowitz, 1985; Silliman, 1989).

Families typically rely on outpatient services to manage patient health problems. Many families lack basic knowledge about how to care for their relatives (Haley, et al., 1992). Caregivers often receive inadequate information about the causes, symptoms, and course of illness, as well as the availability of social support resources to deal with the problems of frail older adults.

What is apparent from the literature is that both patients and caregivers need information about their illness, its natural history, prognosis, treatment regimen, future care needs, and socioemotional support. Physician information-giving and socioemotional support are critical factors not only in deciding how to manage the patient's care, but also in caregivers' continued well-being. Concern for the caregiver beyond patient diagnosis is a challenge of "health caring" as opposed to simply "health care" (Silliman, 1989:238).

## **Method**

### **Setting**

The study site was a Veteran's Administration Regional Medical Center (VA) in the Southeastern United States. Data were gathered between July 1990 and June 1991. Subjects were selected from caregivers who accompanied patients aged 65 and older to the VA's two primary care geriatric outpatient clinics (one morning and one afternoon a week). The VA Center is affiliated with medical and nursing schools. Both clinic settings were under the direction of a general internist with certification of special competency in geriatric medicine. These clinics were staffed by attendings in primary care, rotating internal medicine residents, acting interns, nurses, a social worker, clinical pharmacist, optometrist, dietician, and clinical psychologist, with other disciplines, such as an audiologist, being consulted as needed.

## Sample

A screening strategy was used to insure that subjects were the main or primary caregiver for the patient outside the clinic setting. Caregiver participants were included in the study if: (1) they had accompanied the geriatric patient to the clinic on at least one previous occasion; (2) the patient had at least a 12-month history of current functional impairment requiring the caregiver's assistance; and (3) the caregiver had substantial responsibility for the care of the geriatric patient. The caregivers were interviewed at the clinic separate from the patient. One hundred and eight complete caregiver interviews were conducted. The participation rate was 95.6 percent. Table 1 provides a demographic profile of caregiver subjects and the patients they accompanied.

## Procedures

An interview instrument which took approximately 30 minutes to administer was developed and field tested (Haley, et al., 1992). Caregivers were interviewed individually while the geriatric patients were in the clinic room. The interviews were conducted by the senior author and a trained graduate student whose performance was monitored through intermittent observation of actual interviews.

## Measurement

The interview instrument elicited demographic and descriptive information and an assessment of patient functional capacity—activities of daily living—(Lawton, et al., 1982; see Table 1). Many patients were unable to provide information on their own functional capacities. Thus, for consistency, only caregivers' assessments were used. Caregivers have been proven to be accurate assessors of patient function (Elam, et al., 1991). Caregiver *appraisal of role strain* assessed the degree to which caregiving disrupted normal life roles and relationships. *Caregivers' social supports* distinguished both form and content of support provided to the caregiver by relatives in the last six months (Lin, et al., 1986; Sokolovsky and Cohen, 1981). Checklists of clinic procedures, recommendations and referrals to counseling, community agencies and support groups were used to ascertain a caregiver's knowledge of the medical and social support services provided to the patient.

**Table 1**  
**Profile of Caregivers and Patients (N = 108)**

Characteristic	Caregivers		Patients
<b><u>Demographics</u></b>			
Age	Mean	58.0 years	71.8 years
	SD (Range)	12.6 (26-83)	7.3 (52-97)
Sex	Female	92.6% (100)	0.9% (1)
	Male	7.4 (8)	99.1 (107)
Married	Yes	90.7% (98)	—
	No	9.3 (10)	—
Race	White	77.8% (84)	77.8% (84)
	Nonwhite	22.2 (24)	22.2 (24)
Residence	City	46.3% (50)	—
	Suburb	17.6 (19)	—
	Rural	36.1 (39)	—
Income Above \$15,000 <sup>a</sup>	Yes	42.9% (45)	—
	No	57.1 (60)	—
Education	Mean	10.8 years	—
	SD (Range)	3.2 (2-20)	—
Relationship to patient	Spouse	68.5% (74)	—
	Child	21.3 (23)	—
	Other	10.2 (11)	—
Lives With Patient	Yes	76.9% (83)	—
	No	23.1 (25)	—
Caregiving Duration	Mean	105.4 months	—
	SD (Range)	120.2 (1-576)	—
<b><u>Health Status and Service Use</u></b>			
# of Medical Problems	Mean	—	3.3
	SD (Range)	—	1.6 (1-9)
Duration of Illness	Mean	—	142.4 months
	SD (Range)	—	148.6(1-564)
Duration of clinic use	Mean	—	28.7 months
	SD (Range)	—	38.5 (0-216)
Clinic visits <sup>b</sup>	Mean	—	13.6
	SD (Range)	—	18.5(1-98)
Functional capacity: daily living activities done without help <sup>c</sup>	Mean	—	4.9
	SD (Range)	—	3.8 (0-13)

<sup>a</sup> No response on 3 cases    <sup>b</sup> No response on 15 cases

<sup>c</sup> Includes items from both the Activities of Daily Living (ADL) and Independent Activities of Daily Living (IADL) scales.

A composite scale and three subscales of caregiver satisfaction with the clinic and its physicians are provided. Questions were scored along a 1-5 Likert continuum (strongly disagree to strongly agree), and items were selected on the basis of face validity, factor analysis, and internal consistency. The subscales were: *satisfaction with information on illness*, *physician affect* (sensitivity of the physician to the feelings, needs, and contributions of the caregiver), and *physician reciprocity* (physician communication style, dominance, and control over interaction). In addition to these scales, three single item indicators assessed general satisfaction with medical services, social support services, and overall care. For all scales, negative items were reverse coded so that high scores represented higher levels of satisfaction. Scale statistics are presented in Table 2.

**Table 2**  
Description of Caregiver Satisfaction Scales and Indicators

Variable	Scale Range	Scale Mean	Scale SD	Per		
				Item Mean	Item-to-scale Correlations	Alpha
<b><u>Communication Sub-Scales:</u></b>						
Information on Illness	3-35	25.9	4.8	3.7	.55 - .75	.88
Physician Reciprocity	17-45	34.2	4.5	3.8	.43 - .73	.83
Physician Affect	8-35	23.9	4.9	3.4	.49 - .72	.86
Overall Communication	43-111	84.2	12.6	3.7	.36 - .76	.93
<b><u>Single Item Satisfaction Indicators:</u></b>						
Overall Medical Services	1-5	4.3	0.7	—	—	—
Overall Support Services	1-5	4.0	0.7	—	—	—
Overall Care	1-5	3.9	0.9	—	—	—
<b><u>Caregiver Knowledge Scales:</u></b>						
Report of Number of Medical Services Provided Patient	0-9	4.5	2.3	0.3	.37 - .62	.80
Report of Number of Social Support Services Provided Patient	0-6	2.0	1.5	0.3	.59 - .73	.87
<b><u>Caregiver Stress:</u></b>						
Caregiver Role Strain	8-35	19.1	5.9	2.7	.57 - .71	.86
Support From Relatives	0-6	2.9	2.4	0.5	.65 - .84	.91

## Results

The per-item means for the three satisfaction with communication scales and their composite fell between 3 and 4 (i.e., neutral to satisfied; Table 2). The information on illness subscale indicated that physicians involved most caregivers in the communication process during medical encounters and were especially good at conveying the nature of the patient's condition and explaining medical tests, treatments, and medications. Caregivers also appeared quite satisfied with the level of reciprocity physicians demonstrated during medical encounters. They were especially agreeable that the doctors appeared knowledgeable, spent enough time with them and the patient, listened to them, looked into their concerns, and did not avoid answering questions. Caregivers also felt free to speak their minds and felt that the doctor made it easy for them to speak. But they were slightly less agreeable that they felt free to talk about personal problems.

The positive affect scale had a per-item mean slightly lower than the other two subscales, with more respondents answering in the neutral range. While the caregivers felt understood by the doctor and agreed that the doctor made them feel that what they had to say was important, they were less agreeable that the physicians encouraged them to express their thoughts on the patients' treatments. Furthermore, for many respondents, the doctors failed to assess how a patient's illness impacted on the caregiver. For example, compared to their focus on the patients' medical states, doctors were less likely to ask caregivers how they were coping with the demands made on them by patients, and some physicians appeared insensitive to caregiver stress. Also, doctors often failed to acknowledge a caregiver's contributions to the patient's care.

In summary, this close look at dimensions of caregiver satisfaction revealed caregivers to be generally satisfied with physician communication as it pertained to the patient's medical encounter and condition. What many caregivers perceived to be lacking, however, was an acknowledgment by the physician that the caregiver undergoes much strain in providing support to their patients outside the clinical setting.

### Accounting for Caregiver Satisfaction with Medical Encounters

To explain the variation in our caregiver satisfaction measures, we used stepwise regression on predictor variables. Zero-order correlations are presented in Table 3. The results of the regressions are presented in Table 4. Two sets of statistically significant variables emerged: (1) those related to



**Table 3**  
Zero-order Correlations (Pearson's  $r$ ): Caregiver Satisfaction Scales,  
Knowledge of Clinic Services, and Caregiver and Patient Personal and Situational Variables

	X1	X2	X3	X4	X5	X6	X7	X8	X9	X10	X11	X12	X13	X14	X15
X <sup>1</sup> Satisfaction with information on illness	1.000														
X <sup>2</sup> Satisfaction with physician control	.679 <sup>c</sup>	1.000													
X <sup>3</sup> Positive affect	.653 <sup>c</sup>	.672 <sup>c</sup>	1.000												
X <sup>4</sup> Satisfaction with communication	.882 <sup>c</sup>	.878 <sup>c</sup>	.885 <sup>c</sup>	1.000											
X <sup>5</sup> Overall satisfaction with medical services	.382 <sup>c</sup>	.414 <sup>c</sup>	.429 <sup>c</sup>	.464 <sup>c</sup>	1.000										
X <sup>6</sup> Overall satisfaction with social support services	.432 <sup>c</sup>	.357 <sup>c</sup>	.396 <sup>c</sup>	.469 <sup>c</sup>	.641 <sup>c</sup>	1.000									
X <sup>7</sup> Satisfaction with overall care	.434 <sup>c</sup>	.512 <sup>c</sup>	.402 <sup>c</sup>	.512 <sup>c</sup>	.388 <sup>c</sup>	.204 <sup>a</sup>	1.000								
X <sup>8</sup> Caregiver report of number of medical services provided patient	.205 <sup>a</sup>	.087	.158	.194 <sup>a</sup>	.060	.237 <sup>b</sup>	-.086	1.000							
X <sup>9</sup> Caregiver report of number of social support services provided patient	.159 <sup>a</sup>	.080	.161 <sup>a</sup>	.181 <sup>a</sup>	.178 <sup>a</sup>	.474 <sup>c</sup>	-.088	.533 <sup>c</sup>	1.000						
X <sup>10</sup> Caregiver role strain	.285 <sup>c</sup>	-.366 <sup>c</sup>	-.252 <sup>b</sup>	-.328 <sup>c</sup>	-.168 <sup>a</sup>	-.121	-.349 <sup>c</sup>	.250 <sup>b</sup>	.271 <sup>b</sup>	1.000					
X <sup>11</sup> Patient functional capacity	.190 <sup>a</sup>	.180	.023	.136	.050	-.074	.232 <sup>b</sup>	-.173 <sup>a</sup>	-.409 <sup>c</sup>	-.407 <sup>c</sup>	1.000				
X <sup>12</sup> Number of medical conditions	.014	.172 <sup>a</sup>	-.049	.045	.154	-.071	.066	-.093	-.032	.07	5.071	1.000			
X <sup>13</sup> Patient age	-.092	.120	.061	-.101	-.178 <sup>a</sup>	.000	-.160 <sup>a</sup>	.258 <sup>b</sup>	.207 <sup>a</sup>	.217 <sup>b</sup>	-.228 <sup>b</sup>	.041	1.000		
X <sup>14</sup> Caregiver education scale	.029	.160 <sup>a</sup>	.016	.078	.113	.029	-.030	.033	.054	.085	.052	.000	-.183 <sup>a</sup>	1.000	
X <sup>15</sup> Support from relatives	.148	.153	.207 <sup>a</sup>	.184 <sup>a</sup>	.004	-.132	.037	-.110	.142	.155	.049	.142	-.035	.001	1.000

<sup>a</sup> $p < .05$  <sup>b</sup> $p < .01$  <sup>c</sup> $p < .001$

Table 4

Standardized Regression Coefficients for Caregiver Satisfaction Scales Regressed on (a) Caregiver Knowledge of Clinic Services Provided and (b) Caregiver and Patient Personal and Situational Variables

Independent Variable	Satisfaction with Communication Scales			General Satisfaction Items			
	A Inform- ation on illness	B Physician control	C Positive affect	A+B+C Overall Communi- cation	Overall medical services	Overall support services	Overall care
<b>KNOWLEDGE OF CLINIC SERVICES PROVIDED</b>							
Caregiver report of number of medical services provided to patient	.232 <sup>b</sup>	.156	.169	.221 <sup>b</sup>	.036	.020	.012
Caregiver report of number of social support services provided to patient	.228 <sup>b</sup>	.173	.185	.246 <sup>b</sup>	.273 <sup>b</sup>	.546 <sup>d</sup>	.060
<b>PERSONAL AND SITUATIONAL VARIABLES</b>							
Caregiver appraisal of role strain	-.296 <sup>c</sup>	-.415 <sup>d</sup>	-.306 <sup>c</sup>	-.378 <sup>d</sup>	-.217 <sup>b</sup>	-.261 <sup>c</sup>	-.307 <sup>b</sup>
Patient functional capacity	.179 <sup>a</sup>	.097	-.027	.095	.050	.038	.123
Number of medical conditions	.062	.219 <sup>b</sup>	-.033	.089	.197 <sup>b</sup>	-.014	.108
Patient age	-.090	-.060	-.071	-.091	-.180 <sup>a</sup>	-.054	-.091
Caregiver education	.008	.164 <sup>a</sup>	-.015	.068	.080	.009	-.030
Support from relatives scale	.139	.092	.209 <sup>b</sup>	.164 <sup>a</sup>	-.024	-.095	-.026
<b>SOURCES OF VARIATION</b>							
Knowledge of clinic services	R <sup>2</sup> .045	.009	.033	.046	.034	.225	.004
Personal and situational	R <sup>2</sup> .102	.216	.105	.139	.093	.052	.141
Joint effect	R <sup>2</sup> .085	.057	.044	.088	.034	.029	.006
Total	R <sup>2</sup> .232 <sup>d</sup>	.282 <sup>d</sup>	.182 <sup>b</sup>	.273 <sup>d</sup>	.161 <sup>b</sup>	.306 <sup>d</sup>	.151 <sup>b</sup>

a p < .10 b p < .05 c p < .01 d p < .001

the clinical encounter, measured as a caregiver's knowledge of the clinical services provided the patient, and (2) the personal characteristics of caregiver and patient and the situational variables which impact on the caregiver's role performance and psychological well-being.

On the satisfaction with information on illness scale, caregiver appraisal of role strain was the strongest predictor of satisfaction. Related to caregiver role strain was patient functional capacity, which also influenced satisfaction. In addition, those caregivers with greater knowledge of the medical and social support services provided to the patient were more satisfied.

On the physician reciprocity scale, caregiver appraisal of role strain was again the strongest predictor. Furthermore, the number of patient conditions influenced satisfaction because the more extensive a patient's condition, the greater the opportunity for a caregiver to get involved in the medical aspects of encounters. As long noted in the literature, patients with education levels closer to that of physicians experienced less social distance and seemed better equipped to obtain satisfactory answers to the technical aspects of care that establish physician dominance (Buller and Buller, 1987).

With the positive affect scale, the circumstances of the caregiver seemed to be the important predictors. Caregivers under strain from dealing with their relative's illness were less likely to feel positive toward the physician, while those with greater support from relatives were more likely to feel positive.

The results for the composite scale of overall satisfaction with physician communication paralleled those of its subscales. Caregiver appraisal of role strain was the strongest predictor, with knowledge of medical and social support services and support from relatives explaining additional variation.

For the satisfaction with overall medical services indicator, as one might expect, caregiver's knowledge of these services was strongly related to their satisfaction level. Personal and situational characteristics accounted for additional variation. For the satisfaction with social support services indicator, again caregiver's knowledge of these services was strongly related to their satisfaction. This suggested that an informed caregiver was a satisfied caregiver. Finally, the regression of overall satisfaction with physician care on other variables again revealed caregiving role strain to be an important variable.

At the bottom of Table 4, the amounts of explained variation ( $R^2$ ) in each satisfaction scale are sorted by source, distinguishing clinic-related knowledge variables from personal/situational variables and joint effects, the last reflecting some intercorrelation among the first two sets of variables. The results were striking. For six of the seven measures of satisfaction, personal and situational variables, especially those related to caregiving stress, influenced caregivers'

perceptions of formal care providers more than did the caregivers' knowledge of this formal care. Satisfaction with overall social support services was the only satisfaction measure greatly influenced by actions of clinic personnel, and these services were ones that were less medically related and had a greater influence on what happens to caregivers and patients once they leave the clinic setting.

## Discussion

### Structural Versus Personal Influences on Caregiver Satisfaction

The one outstanding result of the analysis is that personal and situational variables far outweigh clinic-related variables in influencing caregivers' perceptions and attitudes toward physicians and the medical encounter. These findings are important because, while the clinic can control what goes on in the medical encounter itself, the circumstances of the caregiver are less directly influenced by clinic personnel, and may in fact be immutable. Caregiver appraisal of role strain especially stands out. Role strain pertains to what occurs away from the clinics; yet, caregivers' feelings toward the clinics and its physicians are not independent of these external factors. Put another way, what happens to caregivers outside the clinics may greatly influence satisfaction with services inside the clinics. Satisfaction with communication may be more the result of general caregiver well-being than the structure of services.

While the literature fails to provide us with data on caregiver satisfaction with clinical encounters with which to tie our results, it is informative to compare our findings to those of research on patient satisfaction. Specifically, patients who are under more stress and who are more ill tend to be less critical of the care they receive (Buller and Buller, 1987). Conversely, those patients who are healthier and under less stress tend to be more *dissatisfied* with their health care. If previous patient satisfaction findings were comparable to caregivers, one might expect caregivers of less healthy patients to be more satisfied with the care their patients receive. This finding is not supported by the data; a less healthy patient leads to a dissatisfied caregiver, apparently by adding to caregiver role strain. This appears in the negative correlation between satisfaction measures and patient functional capacity, and between functional capacity and caregiver appraisal of role strain (Table 3). Caregiver satisfaction appears distinctive from patient satisfaction.

That patient and caregiver satisfaction are distinct might be related to the complexity of the caregiver role. In terms of role tasks, obligations, and privileges, the caregiver role combines patient *and* provider dimensions. Physicians are likely to interact with caregivers as though the latter were simply extensions of the patient and, thus, bestow sick role obligations on them (Parsons, 1951). For instance, there are unstated assumptions that the caregiver accept the competence of the professional and encourage the patient to seek technically competent help and adhere to medical regimen, even when the patient fails to accept these sick role obligations. At the same time, in some regards the caregiver role is an extension of the physician's. The caregiver is held responsible for providing care tasks to the patient, yet lacks the comprehensive support system that accompanies physicians when they perform a providing role.

The marginal status of caregivers is revealed further by the fact that they lack privileges that characterize the sick role. In fact, there may be an inverse relationship between patient privilege and caregiver privilege. For example, as the patient becomes more ill and gains the privilege of exemption from normal roles, it is at this very time that demands on the caregiver increase. In addition, caregivers certainly lack the privileges that characterize the physician's role. Unlike the physician, the caregiver is not protected from emotional strain by the norm of affective neutrality; thus, the caregiver shares the patient's anxieties. Nor is the caregiver afforded professional dominance; thus, husbands may resist the dominance of their caregiver wives or disregard the caregiving directives of their children. This dilemma of double-edged obligations without consonant privileges is especially detrimental when a caregiver must provide for a patient with low functional capacity. The informality and uncertainty of the caregiver role certainly compounds social psychological strain. The caregiver role is performed outside a structured environment, such as a clinic, and it lacks institutionalized privileges.

As elderly caregiving increases with the aging of the population, one might expect the caregiver role to attain some privileges and take on a structure more conducive to the welfare of both care recipient and caregiver. As it stands now, a clear extrapolation of the obligations and privileges of the caregiver role cannot be derived from the literature. The findings of this study are an initial step in filling that research gap.

This research has policy and practical implications. Medical facilities apparently cannot restrict their activities to the provision of medical services, even where "caring" interaction is stressed. These facilities must make greater efforts to alleviate the external conditions that inhibit beneficial patient prognosis and quality of life. Furthermore, given that family

caregivers are a critical link in the care of the elderly, medical practice must be merged with the caregiver's experience in such a way that the caregiver is recognized as a part of the health care team. Progressive geriatric services must include among their priorities charting the circumstances of the external care environment and assisting caregivers by reducing care strain.

One of the major contributions of these data is the wide range of new research questions they suggest: (1) What do caregivers need to know about the care, treatment, and prognosis of the patient, and who should provide this information? (2) How should services be structured to better accommodate the medical care and informational needs of both elderly patients and their caregivers? (3) What does it mean to the patient when the caregiver is not satisfied? (4) How is the physician-patient relationship affected when a caregiver is involved in any way, and especially when the caregiver is dissatisfied? (5) How important is the physician-caregiver relationship from the point of view of the physician? (6) How do physicians obtain satisfaction while caring for dependent patients? (7) What are the limitations on what a formal care facility can do to enhance caregiver satisfaction when so much depends on things outside the clinic setting?

Since current physician payment systems do not reimburse physician activities like talking, understanding, and socioemotional support, there is a formidable challenge before us. The miscommunication and lack of communication between physicians and patients are well-known and often addressed phenomena. The lack of communication and miscommunication between physicians and caregivers, and patients and caregivers is less often acknowledged or studied.

Whether caregivers are providing primarily instrumental services, such as assistance with activities of daily living, or serving as advocates and providing emotional and/or financial support, when individuals are ill or in crisis, they need the help of others. How physicians, patients, and spouses can be encouraged to confront these difficult issues remains an empirical question. How the formal medical care system can contribute to better informal (i.e., caregiver) care is an immediate practice and policy challenge.

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# Predictors of the Use of Respite Services by Caregivers of Alzheimer's Patients: Racial and Generational Differences\*

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Gary T. Deimling, *The Benjamin Rose Institute*  
Wendy J. Looman, *The Benjamin Rose Institute*

## ABSTRACT

*This research applies one prominent model of service utilization (the Andersen-Newman Model) to better understand the way in which family caregivers utilize respite services when caring for older relatives. Specifically, this research examines racial (black and white) and generational (spouse and adult-child) differences between caregivers of Alzheimer's patients and the volume and type of respite services used. The sample (N= 359) is drawn from six Northeast Ohio programs in a consortium that uses a personal computer-based information system to collect intake, assessment, service use, and program satisfaction data from respite clients. Racial differences are found in client attrition and turnover. Results also show adult-child caregivers are the greatest users of day care. These generational differences persist despite the similarities in patient and caregiver need. Fee subsidy and relationship strain between the caregiver and elder predict the amount of service used. Findings suggest that practitioners need to take into account racial and generational factors in addition to traditional patient and caregiver needs when formulating care plans.*

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## **Respite's Impact on Caregivers**

There has been considerable debate in the gerontological literature about the impact of respite on family caregivers. Callahan (1989), in reviewing the existing evidence for respite's effects (see Lawton, Brody and Saperstein, 1989), asserts that while families are satisfied with this service, there is little compelling evidence that it has measurable impact on caregivers. Deimling (1991), in contrast, argues that methodological impediments in most previous research have prevented the actual benefits of respite from being uncovered. Zarit, et al. (1989) also point out the important role that methodology has played in the failure of research to document the impact of caregiver intervention programs such as respite.

One difficulty in determining the impact of respite on caregivers has been the limited amount of information available on how caregivers utilize respite, in terms of the types (in-home, day care) and volume of service. For example, there has been little research into the ways in which potential respite users move through service systems, from inquiry about service to assessment for service, and actual use of respite. The research that does exist is usually from single, and often small, programs, with limited socio-demographic variability. The lack of size and diversity in the samples has limited the generalizability of findings on how respite is used. Lawton, et al. (1989) have shown that participants in one respite demonstration project used little formal respite and often did not use any more respite from formal sources than other caregivers in their comparison groups received from informal sources. Their research also showed that many families eligible for respite either did not go on to use it, used it sporadically, or for only a very brief period. Before concluding that respite does not have its intended impact, however, we need to know a great deal more about how caregivers use this service.

## **Racial and Generational Differences**

Two other areas where little is known about respite use are racial (black and white) and generational (spouse and adult-child caregiver) differences. With regard to race, the literature on service use documents the reluctance of black families to use services in general, and institutionally based services (such as nursing homes or day care) in particular (Cox and Monk, 1990; Taylor and Chatters, 1986; Neighbors, 1984). The usual explanation for this is that black families are more likely to use informal, familial

sources of assistance. Another explanation is that there are barriers to service use related to the availability and accessibility of services. There has been no research on the use of respite by black families, nor has there been research on minority preferences for in-home or day care as a form of respite.

The caregiving literature provides ample evidence of the differences inherent in being either a spouse or an adult-child caregiver, as well as the implications of living arrangement for caregiver strain and service use (Deimling, et al., 1989; Noelker and Bass, 1989). What is not known is how these structural features affect caregivers' preferences for specific types or volume of services. Given the differences in spouse and adult-child caregivers in terms of competing demands, employment, and the nature of the relationship itself, it would not be surprising to find considerable differences between these two groups of caregivers in their preferences regarding respite service.

In short, there has been little research on the ways in which caregivers use respite services, their flow through the service systems that provide formal respite, and their attrition from these programs. This research will attempt to add to our knowledge of the ways families use respite, and will go further to examine the predictors of type and volume of service use in a relatively large multi-agency sample of respite users.

### **Analytic Model**

In order to organize the analysis, a well-known model of service use, the Andersen model, was employed. The Andersen model (Andersen and Newman, 1973) identifies three categories of factors (predisposing, enabling, and patient need) as potentially influencing the use of formal health care services. While respite is not viewed as a health care service per se, the predictors posited by the model are likely to be involved in the use of other types of formal services, such as respite, which have a health care orientation.

Within the context of this research, the model suggests a range of care recipient (patient) and family characteristics that may be related to the use of respite. The first category of variables identified in the Andersen model, *predisposing factors*, includes patient demographics and other structural variables that can "predispose" an individual to use formal sources of assistance such as respite. It is hypothesized that race, generation, and both caregiver and elder gender are structural features that can affect service use.

The second category of variables, *enabling factors*, are viewed as important predictors of service use because they provide greater opportunity for use. The size of the fee subsidy the family receives is one such variable that enables service use by enhancing affordability. Household size and the number of informal helpers are viewed as having negative effects on service use, in that larger families or those with a larger informal network may not use services because their well-developed informal network meets existing care needs. The number of formal services already being utilized is an enabling characteristic, because families who have prior or current experience with the use of services are more likely to know how to access services and have apparently already resolved for themselves the issue of appropriateness of services.

The third category of variables, which predict service use in the Andersen model, is care recipient *need*. Care recipients with greater objective needs for care are hypothesized to be greater users of service. The elder's age, as well as his or her mental and physical functioning, are three measures that can be used to operationalize the patient's level of need.

Bass and Noelker (1987) made an important adaptation to the Andersen model when they included the need characteristics of family members involved in caregiving. Their adaptation provides a more complete estimate of families' total need for services. In this study, caregiver need is hypothesized to be positively associated with the increased use of respite services.

Taken together, the predisposing, enabling, and need (both care recipient and caregiver) characteristics have the potential to influence the type and volume of respite used. In this research, the primary outcome measures of interest will be whether the respite service is actually used by the patient/family after inquiring about and being assessed for service, the volume of service used, and the type of respite (in-home or day care) ultimately utilized.

## **The Sample**

In mid-1988, the Margaret Blenkner Research Center of The Benjamin Rose Institute began to develop an interagency database with Northeast Ohio programs providing respite service to caregivers of persons with Alzheimer's disease (AD). The information system, entitled SISTERS (Shared Information Systems to Evaluate Respite Services), is comprised of four separate but integrated components: Inquiry, Assessment, Service Delivery, and Client Satisfaction/Quality Assurance.

During the first full year of operation, information was collected from 359 inquiries for service. Of these, 234 families were assessed, and 181 received at least one unit of respite service (4 hours of in-home or 1 day of day care). The data excludes a small number of families ( $n=4$ ) where the racial characteristics of the family were not known or where they were other than white or black.

Chart 1 shows the movement of cases from inquiry through assessment and service use. One of the unique features of the SISTERS information system is its ability to track clients from initial contact through the point of discharge from the service system and to document attrition at any point along the way. The 359 inquiries resulted in 109 cases being assessed (30 percent), 86 of which were assessed immediately and 23 of which were assessed later. These clients joined the existing caseload of 129 clients, who had been assessed prior to the start of the database, so that complete assessment information is available from 234 clients/families.

Not all clients assessed for service ultimately went on to receive service. In fact, there was substantial attrition, with 53 families never receiving service after completing assessment. While a portion of this attrition was due to death of the elder ( $n=4$ ) or nursing home placement ( $n=7$ ), other families chose not to schedule service even though fully qualified to receive it. Over the project's first full year, 43% of the clients left the program. Of these, 10 left because the care recipient died, 22 entered nursing homes, and 45 discontinued participation for a variety of other reasons. These reasons included needing more service than the program provided and needing services other than those the program provided. Other reasons included the caregiver's dissatisfaction with the service or unwillingness to cooperate with the program. A small number of discontinued cases were the result of the care recipient or caregiver moving out of the service area or the inability to pay for subsidized service.

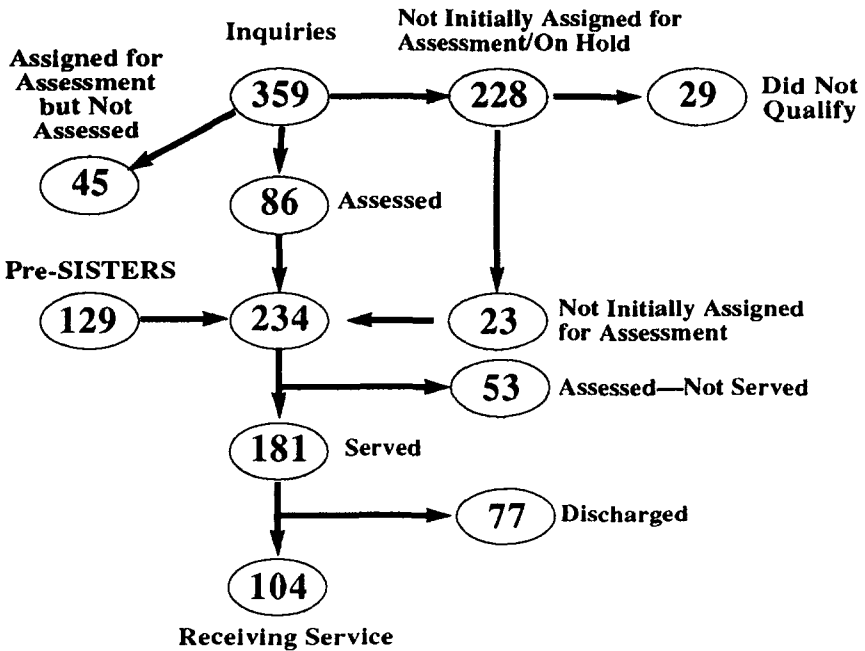
## Measurement

The multidimensional SISTERS assessment instrument was the primary source of information used in the analysis for this paper. It includes extensive demographic and family structure information for each family and a complete listing of other sources of informal and formal assistance used by each care recipient and caregiver.

Each of the respite programs employed a sliding fee scale to determine the extent of fee subsidy provided to the family. The agencies employed the fee scale adopted by the Ohio Department of Aging, as each of the pro-



Chart 1. SISTERS Client Flow



grams utilized State of Ohio funding to underwrite the cost of the program and to provide fee subsidies. These demographic, family structure, assistance use, and fee subsidy measures serve to operationalize the predisposing and enabling variables in this study.

Elder need in terms of cognitive incapacity was measured using the Short Portable Mental Status Questionnaire (SPMSQ) designed by Pfeiffer (1975). Physical functioning was measured using the Personal Self-Maintenance (PSM) items developed by Lawton and Brody (1969). In addition to caregiver age, other measures of caregiver need were derived from prior family care research at The Benjamin Rose Institute (see Deimling, et al., 1989; Bass and Noelker, 1987; Deimling and Bass, 1986; Poulshock and Deimling, 1984). These measures included a single-item, self-report indicator of physical health decline and a single-item indicator of emotional health decline. A four-item measure of relationship strain (alpha =.64) and a three-item index of activity restrictions (alpha =.70) were also included. Finally, information on the total number of hours of service, the average monthly hours of service, and the type of service used were obtained from the Service Delivery component of the information system.

## Analysis Strategy

The analysis in this paper focuses on the factors associated with the use of service, particularly the volume and type of respite used. In examining these predictors, the first step was to identify those predisposing, enabling, and need characteristics of families/patients/caregivers that differentiated service users from non-users. Descriptive information was used to compare these two groups along with correlational data for all clients assessed for service.

The second step in the analysis was to identify the correlates of the volume and type of service used (day care or in-home). The correlational analysis was the first procedure used, leading to a selection of variables for inclusion in a multivariate analysis of the predictors of service use. Because of the interval nature of the service volume variable, regression analysis was employed. To examine categorical measures, i.e., service use/non-use and service type (day care or in-home), discriminant function analysis was used.

## Findings

### Service Use/Non-use

Table 1 displays the characteristics of patients and caregivers in families who used respite services after being assessed and those who did not use respite services after completing the assessment process. This descriptive data shows that the proportion of blacks who were assessed but chose not to use respite services was substantially greater (47.2 percent) than blacks who chose to use the service after assessment (35.4 percent). Thus, black families were less likely to use service after assessment than white families.

The proportion of spouse caregivers differed substantially between the served (50.8 percent) and unserved groups (39.6 percent). After assessment, spouse caregivers were more likely to go on to use respite than adult-child caregivers. Neither elder nor caregiver gender differentiated the groups who chose and those who did not choose to use service. However, in terms of two of the predisposing variables, race and generation, there were substantial differences in the proportion who chose to use respite after assessment.

Another substantial difference between those served and those not served was the proportion of families already using formal assistance. In the group who used service after assessment, nearly half had two or more

**Table 1**  
 Family, Patient, Caregiver and Service Use Characteristics by Service Status

	Served (n=181)	Not Served (n=53)	p <sup>a</sup>
<b><u>Predisposing</u></b>			
% Black	35.4	47.2	.12
% Spouse caregiver	50.8	39.6	.15
% Caregiver female	76.2	77.4	.87
% Patient female	56.9	60.4	.65
<b><u>Enabling</u></b>			
Fee subsidized 80%+	49.6	43.9	.33
Mean household size	2.4	2.8	.01
% 2+ informal helpers	63.0	67.9	.51
% 2+ formal helpers	45.3	58.5	.09
<b><u>Patient need</u></b>			
Mean age	78.0	78.7	.62
Mean SPMSQ Errors (0-10 errors)	7.3	7.2	.58
Mean PSM (0-6, low to high independence)	2.7	2.8	.72
<b><u>Caregiver need</u></b>			
Mean age	62.1	59.5	.43
% Physical health decline	46.0	38.3	.36
% Emotional health decline	67.9	72.3	.66
Mean relationship strain (0-8, low to high strain)	2.2	2.4	.28
Mean activity restriction (0-3, low to high restriction)	2.2	2.5	.03
<b><u>Service</u></b>			
Mean hours	232.6	NA	
Mean hours per month	31.4	NA	
% using in-home <sup>b</sup>	55.2	NA	
% using day care <sup>b</sup>	47.0	NA	

<sup>a</sup> Determined using Chi-square statistics for % variables and t test for mean.

<sup>b</sup> Does not total 100% due to multiple types of respite use by some families.

formal sources of assistance, indicating that they were receiving service from at least one other formal source in addition to the respite program. Among those families who did not use respite, well over half already received service from at least one other formal source.

In terms of other enabling characteristics, such as fee subsidy, household size, and the number of informal helpers, the served group did not differ substantially from the unserved group. The fact that the fee subsidy did not differentiate the use of service was counterintuitive. The availability of the fee subsidy was expected to encourage families to use respite service.

Also somewhat surprisingly, patient need did not differentiate significantly between the group that chose to use service after assessment and those that chose not to use respite. The data show that the elders in this sample were substantially cognitively impaired (e.g., SPMSQ errors of 7.3 and 7.2 items out of 10). On average, the elders in this sample were able to perform fewer than three out of six self-maintenance tasks.

There was one notable difference between the two groups with respect to caregiver need. The group who chose to use respite was more likely to report *physical health decline in the preceding months compared to those who chose not to use service*. This is in contrast to other measures of caregiver strain, in which the general pattern is that the group not using respite is more likely to report emotional health decline, relationship strain, or activity restriction.

### Correlates of Service Volume and Type of Respite Used

Among service users, the correlates of volume of service used and type of respite (day care or in-home) were identified. The same predisposing, enabling, elder and caregiver need characteristics were examined. The measure of service volume used in this portion of the analysis was the average number of hours of respite used by the caregiver per month. In the previous table race was associated with whether or not a caregiver used respite. The correlational data show that, among those using respite, race was not associated with the volume of service. Thus, while black families were less likely to use service than white families after assessment, once in the service program, their volume of service use was not significantly different from that of white families.

In the prior table, spouse caregivers were shown to be more likely to use respite after assessment than adult-child caregivers. The correlational data in Table 2 show, however, that once spouse caregivers began to use services, they used significantly less service than adult-child caregivers.

**Table 2**  
 Correlation Matrix of Family, Patient, Caregiver, and Service Use Characteristics  
 All Clients Assessed (n=234) Served Clients Only (n=181)

			Received Service	Average Service	Day care	In-home
<b>Predisposing</b>	<u>Mean</u>	<u>Std.</u>	<u>r</u>	<u>r</u>	<u>r</u>	<u>r</u>
Race (black)	.38	.49	-.10	-.09	.14*	-.08
Spouse caregiver	.48	.50	.09	-.18**	-.25**	.23**
Caregiver female	.77	.42	-.01	-.06	.01	-.01
Patient female	.58	.50	-.03	.13*	.08	-.09
<b>Enabling</b>						
Fee subsidized 80%+	45.15	37.35	-.06	.23**	.36**	-.37**
Household size	2.47	.96	-.18**	.14*	.16**	-.13*
# informal helpers	1.92	.80	-.00	.11	.10	-.11
# formal helpers	1.62	.72	-.09	-.20**	-.25**	.24**
<b>Patient need</b>						
Age	78.12	9.05	-.03	.00	-.12*	.12*
SPMSQ errors	7.31	2.80	.01	-.17**	-.29**	.30**
PSM	2.74	2.05	-.01	.20**	.36**	-.35**
<b>Caregiver need</b>						
Age	61.52	14.64	.07	-.14*	-.23**	.19**
Physical health decline	3.47	.67	.03	-.07	-.16*	.13*
Emotional health decline	3.78	.83	-.02	.02	-.05	.05
Relationship strain	2.24	1.91	-.05	.20**	.09	-.09
Activity restriction	2.23	1.05	-.12*	-.08	-.22**	.22**
<b>Service</b>						
Average service	31.35	30.34	—	—	.40**	-.38**
Day care	.36	.48	.41**	.40**	—	-.96**
In-home	.43	.50	.47**	-.38*	-.96**	—

\*p < .05; \*\*p < .01.

Conversely, then, adult-child caregivers were less likely to use service after assessment than spouse caregivers, but once they began using services they used a greater volume of service than spouse caregivers. While neither the gender of the caregiver nor that of the elder differentiated the service use/non-use groups, families in which the elder was female used significantly more service than when the elder was male.

Three of the four enabling characteristics were significantly associated with the volume of service used. Fee subsidy, which did not differentiate

the use/non-use groups, was significantly correlated with the volume of use. The greater the fee subsidy, the greater the volume of service. Household size was also positively associated with service volume. Surprisingly, larger households used more respite. This may be related to the fact that adult children used more respite and these households were likely to be larger due to the presence of third generation children. It may also be due to the fact that adult-child caregivers often were employed and thus used respite not as respite per se, but rather to enable them to work. When caregivers use respite to continue employment they may need a greater number of hours of service to cover their work schedule.

While patient need variables were not associated with the use or non-use of service, they were significantly associated with the volume of service used. For example, cognitive impairment was significantly associated with volume of use. However, the negative sign of the coefficient indicates that families of more cognitively impaired individuals used less service than families of less impaired individuals. The PSM indicator suggests the same is true for physical functioning. Families where elders were able to do more for themselves (higher PSM score) used more respite. In both situations, what was apparently occurring was that high levels of impairment prohibited the use of respite in these families. The extreme impairment of the Alzheimer's patient may mean that the caregiver did not feel comfortable leaving the patient for even a short period, and day care may be inappropriate for those with higher levels of impairment.

With regard to caregiver need, older caregivers used significantly less respite than younger caregivers. Those who reported the greatest relationship strain used more respite than those reporting less relationship strain. Surprisingly, neither physical nor emotional health decline were significantly correlated with service volume, and neither was the caregiver's activity restriction.

Finally, the average volume of service was positively associated with the use of day care and negatively associated with the use of in-home service. This indicates that day care users, in fact, used significantly more service on average than did in-home service users.

The remaining correlational analysis looks at the association between the predisposing, enabling, and need variables on the family's choice to use either day care or in-home service. Few families used a combination of both services, so the predictors of the use of one form of respite are the reciprocal of their non-use of the other form of respite. As a result, the coefficients, in general, were very similar in magnitude for the two groups, with only the reversed sign indicating use or non-use of that specific form of respite.

**Table 3**  
Discriminant Function Analysis of Service Use/Non-Use

Standardized Canonical  
Discriminant Function Coefficients

Predisposing

Race (black)	.-15
Spouse caregiver	-.24
Elder female	-.01

Enabling

Fee subsidized 80%+	.30
Household size	.51
# Formal helpers	.35

Elder need

Age	.10
SPMSQ Errors	-.12
PSM	.23

Caregiver need

Age	.02
Physical health decline	-.33
Relationship strain	.11
Activity restriction	.64

Actual Service Use	Predicted Service Use	
	<u>No</u>	<u>Yes</u>
No	6 14.3%	36 85.7%
Yes	4 28.0%	140 97.2%

Overall percent classified correctly = 78.5%

Race and generation were again significant predictors, with blacks more likely to use day care and spouses more likely to use in-home service. Fee subsidy correlated with the use of day care, with families receiving greater subsidy more likely to use day care. Also, larger families were more likely to use day care. With regard to patient need, families with the oldest, most cognitively impaired, and least functionally independent elders were most likely to use in-home respite. For caregivers, the oldest and those with the greatest health decline and activity restriction were most likely to use in-home respite.

**Table 4**  
 Predictors of the Average Monthly Volume of Service Use (N = 181)

	Volume of Service Use	
	<u>beta</u>	<u>p</u>
<u>Predisposing</u>		
Race (black)	-.09	.28
Spouse caregiver	-.04	.76
Patient female	.12	.15
<u>Enabling</u>		
Fee subsidized 80%+	.18	.01
Household size	.01	.88
# Formal helpers	-.13	.10
<u>Patient need</u>		
Age	.07	.43
SPMSQ errors	-.13	.11
PSM	.07	.40
<u>Caregiver need</u>		
Age	-.10	.39
Physical health decline	-.01	.91
Relationship strain	.16	.04
Activity restriction	-.03	.68
	<u>R</u>	<u>R<sup>2</sup></u>
	.43	.19
		<u>p</u>
		.001

### Multivariate analysis

Based on the descriptive and correlational analysis just presented, those predisposing, enabling, and need factors that were significantly associated with either service use/non-use, volume of service, or type of service were included in the multivariate analysis. The purpose of this analysis was to determine the net and relative impact of the predisposing, enabling, and need factors, as well as to determine the total impact of all of these factors in explaining the respective service use outcomes. As noted earlier, discriminant function analysis was used with the categorical outcomes (i.e., service use/non-use and in-home/day care) while regression was used with the interval outcome, service volume.

Looking first at Table 3, the results of discriminant function analysis point to the relative importance of caregiver activity restriction and household size in the decision to use service. Caregivers experiencing more activity restriction and those in larger households were more likely to use



**Table 5**  
**Discriminant Function Analysis of the Use of In-home/Day Care Service**

		<u>Standardized Canonical Discriminant Function Coefficients</u>	
<u>Predisposing</u>			
	Race (black)		-.18
	Spouse caregiver		.18
	Patient female		-.02
<u>Enabling</u>			
	Fee subsidized 80%+		-.63
	Household size		.13
	# Formal helpers		.24
<u>Patient need</u>			
	Age		.12
	SPMSQ Errors		.29
	PSM		-.47
<u>Caregiver need</u>			
	Age		.21
	Physical health decline		.18
	Relationship strain		-.15
	Activity restriction		.21
		Predicted Service Use	
	Actual Service Use	<u>No</u>	<u>Yes</u>
	In-Home	53	14
		79.1%	20.9%
	Day Care	24	49
		32.9%	67.1%

Overall percent classified correctly = 72.9%

respite after completing assessment. The discriminant function utilizing the same thirteen variables correctly classified nearly 80 percent of the cases in terms of actual service use.

The regression analysis in Table 4 shows that the best indicators of service volume were fee subsidy and relationship strain. Race and generation had much weaker and non-significant effects. While the net effects of the remaining indicators were similarly weak, together the equation explained nearly 20 percent of the total variance in service volume.

In Table 5, with regard to type of service used, the results of the discriminant function analysis show that fee subsidy had the greatest relative

impact, with those receiving a larger fee subsidy more likely to use day care. The second most powerful discriminating factor was the elder's physical functioning, with elders having the fewest self maintenance dependencies most likely to use day care. Similarly, cognitive impairment was an important discriminant, with the most mentally impaired least likely to use day care. Overall, the function correctly classified over 70 percent of the cases, being most accurate in predicting in-home service use.

## **Discussion and Summary**

The findings presented here have important implications for those planning respite services for caregivers. First, respite services are used quite differently by spouse and adult-child caregivers. As caregivers, their needs are very different. For adult children, typically daughters, trying to balance a career, the needs of their own children, and those of their parent(s), respite is not actually "respite" from caregiving, but rather an opportunity to meet other obligations. Since most of the adult-child caregivers are employed, respite hours need to be expanded to more closely match the 8-plus-hour work day. For employed caregivers to actually use respite as relief, it may need to be scheduled on weekends. Currently, most respite programs, including all of those in this study, do not have weekend hours.

The results of this research clearly show the preference of adult-child caregivers for day care, while spouse caregivers are more likely to utilize in-home services. The caregivers' ability to utilize day care requires them to prepare the patient for the trip to the day care center, provide transportation (when not provided by the program), and then make the same preparations for the return trip. Adult children are more likely to have the capacity to accomplish these related tasks, in contrast to spouse caregivers. Further, some expressed a reluctance to leave the older person and others indicated that the patient refused to leave the home to go to day care. Thus, in-home services are better able to accommodate these needs. Clearly, in the case of respite, "one size" does not fit all. Practitioners and planners need to recognize these very different needs of spouse and adult-child caregivers.

Racial differences were also noted in the findings. Black families were less likely than white families to go on to use services after assessment. From a practitioner's perspective, it is important to work with minority families during this critical period to ensure that there are no real or perceived

barriers to their use of the service. Our analysis shows that once black families began using service, they used it in similar volume compared to white families. However, black caregivers did show a modest preference for day care as a form of respite. This may be because black caregivers in this study were slightly more likely to be adult children and employed, both potential factors related to the choice of day care over in-home respite. In any event, practitioners and planners need to be aware of these potentially significant black/white differences in preference when formulating care plans and designing programs.

This research shows that there was considerable attrition between assessment and the use of service for all caregivers. This attrition was greatest, however, among minority families. The findings suggest that practitioners need to work with this group of caregivers to assist them in recognizing their own needs for respite and in making plans to use the respite service that is available to them.

While neither minority status nor generation were significant predictors of the volume of service used, fee subsidy and relationship strain between the caregiver and elder were important predictors of the amount of respite used by caregivers. With regard to fee subsidy, our finding that families who received a service in which the cost was partly or totally subsidized used a higher volume of services is hardly surprising. However, this does suggest that the need for respite far exceeds the capacity of most families to pay for the service. If affordable services are made available, they will be used. We can only speculate that a substantial number of minority families who inquired about respite and were assessed for service did not go on to use the service because they felt the need to conserve scarce financial resources.

The relationship between caregiver strain and volume of service use is also not surprising. It does emphasize the importance of collecting caregiver strain information at assessment so that the volume of service required to meet caregiver needs can be efficiently planned. Caregiver strain information may also be useful for practitioners in determining the need for ancillary services such as support groups, counseling, or educational programs. These types of ancillary services can have a multiplier effect on the impact of respite, as they can enhance the caregivers' effective use of the limited respite they do receive.

Our findings also show that day care users consumed more hours of service. This was due, in part, to the fact that day care typically offered only large blocks of time (six or more hours) while in-home respite was often only available in smaller units (typically four hours). It may also suggest,

however, that caregivers used day care as a form of respite when they needed larger blocks of time (e.g., so they could work). This suggests the question: if in-home respite was available in larger blocks of time, would adult-child caregivers be more likely to use it than day care?

In summary, this research serves as an example of the ways in which theoretical models such as the Andersen and Newman model and multivariate statistics can be used with data derived from an information system to examine important clinical questions in gerontology and community-based services for the elderly. The data presented here represent a first step in our attempt to understand the predictors of the types and volume of service use and attrition patterns among families caring for Alzheimer's patients.

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