# Social and economic incentives for family caregivers

by Amy Horowitz and Lois W. Shindelman

*The recent emphasis on developing programs and policies to support families who care for aged relatives makes it important to understand the families' receptivity to the specific social and economic incentives under consideration.*

*The research reported in this paper draws on the experiences of 203 individuals identified as the primary caregiver to an aged frail relative currently receiving home care or day care services in New York City. As part of a larger study of caregiving behavior, respondents were asked to rank their preferences for various service and economic support programs.*

*Findings indicate that family caregivers perceive service and social supports, specifically medical care and homemaker service, as more crucial than both direct and indirect financial incentives. Furthermore, the issue of economic incentives elicited an extremely negative reaction from a significant minority who refused to consider such support in their personal family situations. The analysis indicated that the caregiver's background characteristics were not critical in differentiating caregivers who select either a service or an economic incentive. Among the set of variables defining the current caregiving situation, only sex of the aged relative and utilization of home care services were significantly related to choice of program. Respondents caring for females and high service utilizers were more likely to prefer service supports. Relevance of findings to current policy initiatives regarding financial incentives to families are presented.*

## Introduction

The dual concerns regarding escalating health care costs and the quality of care afforded aged Americans, has placed a primary emphasis on developing cost-effective approaches to meet the long-term care needs of the frail elderly in the community.

An interesting development in these policy discussions over the past several years has been the expansion of the target population to include not only the elderly, but their families as well. Government officials on both the Federal and State level are now considering the development of public programs and policies to support families caring for aged relatives.

This relatively recent emphasis on family-oriented services and incentives is based upon the growing body of knowledge regarding the role families play in providing care to the frail elderly. It has now been established that families are the predominant service and health care providers to the impaired elderly living in the community (Cantor, 1975; Hill, et al., 1970; Rosnow, 1967; Shanas, et al., 1968; Sussman, 1965; Townsend, 1965). Findings from a comprehensive study on cost comparisons of home care show that family and friends expend far more dollars than do agencies for maintaining elderly members at home and have been absorbing the largest portion of the cost compared to the expenditure of institutional dollars (U.S. General Accounting Office, 1977). Furthermore, the availability of a family support system consistently emerges as the primary factor in reducing the probability of institutionalization for the chronically ill aged person (Barney, 1977; Brody, 1966; Spark and Brody, 1970; Townsend, 1965; York, 1977).

Yet, the available evidence also indicates that relatives take on these responsibilities to the detriment of other responsibilities to self and family. They make extensive sacrifices in order to maintain their aged relatives in the community. Often these sacrifices can not be sustained indefinitely. Several studies have shown that the precipitator of institutional placement is more often exhaustion of family resources and excessive burden on family members than a change in the aged person's health status (Brody, 1966; Kraus, et al., 1976; Silverstone, 1978; Teresi, et al., 1978).

Furthermore, changing demographic trends promise to increase current pressures on families (Callahan, et al., 1980, Glick, 1979). Projections include an increase in the proportion of the most vulnerable segment of the elderly population, coupled with a decrease in family size. This is further complicated by an increase in the proportion of women who work and who are thus unavailable as full time caregivers to the elderly. All these trends will limit the ability of families to maintain aged relatives without support, regardless of their desire to do so.

These pressures on families, combined with those on the public purse due to the rising costs of institutional care, have led to the recent concern with developing programs which will encourage and support families to care for aged relatives.

At the current time, actual efforts in this direction are minimal. Service supports to families have largely been offered through local, small-scale programs with time-limited funding.[1] Efforts at direct financial payments to

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[1] An example of such a program is the Natural Supports Project of the Community Service Society of New York. This was a 3-year research demonstration program funded by the Administration on Aging to provide respite and support services to families caring for an aged relative. Program operation was limited to New York City area and only 96 families were served during the life of the project. Although the evaluators concluded that "services were strong incentives for families to resist nursing home placement," program operation was terminated at the end of the funding period. (Frankfather, et al., 1981).

families have been somewhat broader-based but still limited in focus. For example, the State of Maryland is currently operating a demonstration project offering cash grants to a limited number of families who care for an aged relative in their own home. New York State also has experience with cash grants through its home attendant program which has allowed the aged client to choose his/her own home attendant. The latter may be a family member who is subsequently reimbursed by the State through a dual-payee check. Only California has a statewide system, in operation since 1958, which provides relatively high levels of reimbursement for family-based attendant care. However, due to administrative problems and issues of accountability, there are currently efforts in the State legislature to overhaul this program (Callahan, et al., 1980).

Given these scattered efforts, the relative advantages of these different types of service and financial approaches remains more a subject of debate than of analysis at the current time. Furthermore, the eventual efficiency of these programs may depend on the extent to which they are, in fact, perceived as desirable by the families to whom they are targeted. Little data currently exists regarding the preferences of families actually caring for an aged relative.

Thus, the research reported in this paper address two major questions: which supports do families identify as most critical to sustain their caregiving efforts and do such preferences vary by the characteristics of the family caregiver and/or the caregiving situation?

# Research strategy

## Background

This research is drawn from a larger study entitled *The Role of Families in Providing Long-Term Care to the Frail Elderly Living in the Community,* funded by the Health Care Financing Administration. Data were collected during 1980. As part of an indepth interview exploring various aspects of the caregiving experience, relatives were asked to rank their preference for specified service and economic support programs. These items replicated those included in Sussman's research studies on *Family Environments for the Elderly* (1977; 1979).

Respondents were first presented with description of five economic programs and asked to rank them in order of their preference. These programs were presented to the respondent in the format below:

- Rental or property tax deduction—You would be able to deduct a portion of your rent or property tax based on how much space in your home is used by the older person.
- Food stamps—You could buy food stamps for the older person and the family where the older person lives. This would allow you to buy food worth more money than the price of the stamps.
- Monthly check—You would get $200 to $400 each month to help pay for the expenses and extra time spent to care for your older relative.
- Tax deduction—You could deduct up to $1,500 from your income tax to cover expenses of caring for your older relative.
- Low cost home improvement loan—You could improve your home in order to take in an older person and pay a low rate of interest if borrowing money for home improvement was necessary. The government would then reimburse you up to 90 percent of the interest costs.

They were then asked to do the same for the following service progams:

- General services—This program would provide chore services (minor home repairs, heavy cleaning, yard and walk maintenance) meals on wheels, friendly visitors, telephone reassurance, escort service, shopping services and transportation.
- Medical care—This service would provide medical care to your older relative by either a doctor or nurse coming to the home if the older person were housebound, or transportation to a nearby medical center and subsequent care.
- Homemaker service—This would include housekeeping (light cleaning of house, light laundry, clothing repairs, ironing, etc.); homemaking (child care, money management, food planning, shopping, etc.); and personal care (bathing, dressing, feeding, grooming, hair washing and setting, medication, shaving, etc.).
- Community planning agency—A place to help families learn about available services for older relatives. It would help families get these services when needed and help solve some of the problems that could arise from providing care for an older relative.
- Social center—A place for the aged person to do things with others away from the home. The center could also give care and/or supervision while you were away during the day. Transportation between home and the center and a hot meal also would be provided.

In addition to the five service programs included in Sussman's work, a sixth was added to the current study. This was a short-term care center, defined as a residential center where the relative could stay for up to 3 weeks in order to give the family respite or time for vacation.

After ranking both sets of programs separately, respondents were then asked to consider all the service and economic programs together and select the one program they preferred.

Sussman's findings indicated that medical care was the preferred service support while the monthly check was the preferred financial program. When all programs were considered together the overwhelming majority chose the monthly check as most desirable, thus indicating a clear preference for the flexibility of a financial incentive.

However, it is important to note that Sussman's primary samples consisted of individuals randomly selected from community residents, and responding to hypothetical situations of caregiving. Only one small

subsample of 27 were families currently involved in providing care to an elderly relative. Within this group, Sussman found that:

> "The sample of respondents currently caring for an older person place the greatest emphasis on medical care and the social center, with only 11.1 percent indicating that the monthly check is most desirable. This pattern might suggest that while the obvious benefits of the monthly check are recognized by many respondents, actual experience with chronically ill older people might result in a greater appreciation of service supports, such as medical care and a social center."

The purpose of the research being presented here was to replicate these items with a larger sample of current caregivers to determine if this trend would persist.

## Sample design and characteristics

The current sample consisted of 203 individuals identified as the primary caregiving relative to an aged person currently receiving home or day care services in New York City. Four social and/or health care agencies were selected as sampling sites. These included a day care center for the frail elderly; a homemaker/housekeeper provider; a community chore service; and a visiting nurse service. The first two agencies served a Medicaid-eligible population, the third was funded under Title III to address the needs of those slightly above Medicaid eligibility; and the last provided nursing and health care services to Medicaid, Medicare as well as private pay clients. With minor variations between sites, the general sampling procedure consisted of drawing a random sample of aged clients, initiating contact with these clients in order to identify their primary caregiving relative; and contacting the relative to secure cooperation. Within the initial sample of aged clients, 22 percent were found to lack a family caregiver. This group included the kinless, those with no kin in the Greater New York Area, and those with no functional kin. Of the remaining aged clients, 67 percent gave permission to contact their relative and 71 percent of these relatives agreed to participate in the study. Data were collected by way of an indepth structured interview, administered by trained social workers, and taking approximately 2 hours to complete.

Of the respondents, 65 percent were adult offspring (three-fourths of whom were daughters); 9 percent were spouses; and the remaining 26 percent were more distant relatives, primarily siblings, nieces and nephews. The age of the caregivers ranged from 22 to 85 with a mean age of 54.6 for the total sample. The average age of caregiving spouses was 71.4, while among the adult children and other relatives it was 50.8 and 58.2, respectively. Approximately eight out of ten respondents were female; 62 percent were white, 21 percent Black, and 17 percent Hispanic. Excluding spouses caring for a husband or wife, 55 percent of the remaining caregivers were currently married, and 61 percent were working either full or part-time. Family income ranged from under $3,000 anually to more than $30,000, with caregiving spouses concentrated in the lower income categories. The majority of the total sample (69 percent) maintained a separate household from their aged relative. Providing care within a shared living arrangement was the case, however, for all spouses, 27 percent of the adult children, and 15 percent of other relatives. The aged relative in need of care tended to be female (80 percent), widowed (67 percent), 75 years of age or over (66 percent), and at least moderately impaired in activities of daily living (ADL).

## Analysis

The data was initially explored in order to answer two general questions: which social and economic supports are most preferred by families confronted with the care of an ailing relative and which factors influence whether an economic or service support is perceived as most desirable? A third question emerged as it became apparent that the response pattern within this section was unique from the rest of the interview. That is, an extremely high refusal rate was in evidence for the section on economic incentives. The very fact that a significant proportion of respondents were reluctant to address the issue of economic incentives was considered an important finding. The question was then raised regarding the identification of variables associated with nonresponse.

The variables which were examined were conceptually classified into two major categories. The first category consisted of those variables which defined the respondent's predisposition for selecting a specific type of program in terms of their sociodemographic characteristics. These characteristics included the caregiver's age, race, marital status, sex, family income, and relationship to the aged relative.

The second category included factors that defined the respondent's current caregiving circumstances that were viewed as potentially modifying the type and extent of support perceived as most desirable. These variables included the aged person's sex, activities of daily living (ADL) functioning, and current utilization of service supports; the respondent's level of caregiving involvement, degree of preceived stress, as well as their employment status, and living arrangements in relation to their aged relative.

Most variables were measured using single-item indicators with the exception of ADL impairment, service utilization, caregiving involvement, and caregiving stress. For these variables, multi-item scales or indexes were developed to operationalize the construct. All scales were analyzed for internal consistency using Cronbach's alpha to assess reliability of measurement.[2]

# Results

## Selection of preferred program

Looking first within the general category of economic incentives, it is clearly the monthly check that seems the most attractive (Table 1). Forty-four percent of those responding ranked the monthly check as first and almost

[2]See Technical Note for description of scales.

three-quarters (74 percent) chose this program as either first or second. The second most popular economic program was food stamps, with 23 percent ranking it as most preferred and 54 percent as either their first or second choice. The popularity of these two programs suggest that the caregivers recognize the relative benefits of direct income supplementation when compared with the more indirect programs offering tax deductions on income or property. The low-cost housing improvement loan was least preferred, with only 5 percent ranking it as first and more than half (58 percent) placing it at the bottom of the list.[3]

The patterns that emerge among the economic supports are generally consistent with those identified in Sussman's research. The pattern shows a little less consistency when we turn to the service programs (Table 1).

**Table 1**

**Percent distribution on preference for economic and service support programs**

| Program | Percent ranking program as first | Percent ranking program as second |
|---|---|---|
| **Economic programs** | | |
| Monthly check | 44.0 | 29.9 |
| Food stamps | 22.5 | 31.6 |
| Income tax deduction | 17.6 | 18.6 |
| Rental or property tax deduction | 11.0 | 13.6 |
| Low-cost housing improvement loan | 4.9 | 6.2 |
| Total | 100.0 | 100.0 |
| (n) | (182) | (177) |
| **Service programs** | | |
| Medical care | 33.5 | 30.3 |
| Homemaking | 31.5 | 30.8 |
| Social center | 14.0 | 12.1 |
| General services | 11.5 | 13.1 |
| Community planning agency | 8.0 | 5.6 |
| Short-term care center | 1.5 | 8.1 |
| Total | 100.0 | 100.0 |
| (n) | (200) | (198) |

While Sussman's findings show medical care as the service support preferred by the large majority of his combined samples, in our group of family caregivers we see an even split between medical care and homemaking services, with approximately one-third ranking each as first. Almost two-thirds of the respondents chose one of these two programs as either the most, or the second most, preferred. The short-term care center was seen as the least critical service support by relatives. More than three-fourths ranked it as either their fifth or last choice. Only 2 percent chose the short-term care center as the most desirable program, while another 8 percent ranked it as their second choice. This last finding, as well as the emphasis placed on homemaker services, suggests that while extended respite may be desirable, the primary need of caregiving relatives is relief from the daily responsibilities of providing assistance to an aged relative.

The contrast with Sussman's community samples is most striking, however, when we look at the program selected as most desirable by family members. When asked to consider all programs together, both economic and service, over 80 percent of our respondents chose a service rather than financial support. No matter how attractive the financial aid offered by a regular cash supplement, it is clearly less desirable than programs which offer direct assistance with care-related tasks (Table 2).

**Table 2**

**Percent distribution on program selected as most desirable, by relationship of respondent**

| Program | Relationship | | | |
|---|---|---|---|---|
| | Total sample | Spouse | Children | Other relative |
| **Economic programs** | | | | |
| Monthly check | 10.1 | 15.8 | 9.3 | 10.0 |
| Food stamps | 5.6 | .0 | 7.0 | 4.0 |
| Income tax deduction | 1.5 | 5.3 | .8 | 2.0 |
| Rental or property tax deduction | 2.0 | 5.3 | 1.5 | 2.0 |
| Low-cost housing improvement loan | 1.0 | .0 | 1.5 | .0 |
| (Economic subtotal) | (20.2) | (26.4) | (20.1) | (18.0) |
| **Service programs** | | | | |
| Homemaker | 26.3 | 10.5 | 24.0 | 38.0 |
| Medical care | 25.3 | 52.6 | 23.3 | 20.0 |
| Social center | 12.1 | .0 | 15.5 | 8.0 |
| General services | 9.1 | 5.3 | 9.3 | 10.0 |
| Community planning center | 4.0 | 5.3 | 3.9 | 4.0 |
| Short-term center | 3.0 | .0 | 3.9 | 2.0 |
| (Service subtotal) | (79.8) | (73.7) | (79.9) | (82.0) |
| (n) | (198) | (19) | (129) | (50) |

Specifically, 26 percent of the total sample selected homemaking as the most preferred program, 25 percent selected medical care, 12 percent chose the social center, and only 10 percent identified the monthly check as the program liked best.

While spouses were most likely, as compared to children and other relatives, to choose a monthly check as the most preferred support, this was still true of only 16 percent of the spouses. In contrast, more than half of the spouses (53 percent) selected medical care as the most desirable program. Children and other relatives were more likely to put an emphasis on homemaker services, and adult children were more likely than the other two groups of caregivers to cite a preference for a social center (Table 2). The remaining programs were each selected by less than 10 percent of all study respondents. Overall, the initial analyses of our data

[3]The response to the low-cost housing improvement loan is, in all probability, a function of the urban character of the study sample. Most respondents were apartment dwellers and renters. This program would, therefore, only be potentially attractive to the 22 percent who indicated home ownership.

confirm that among individuals actually confronted with the care for an aged relative service and social supports are perceived as more crucial than financial incentives.

## Refusals

The response pattern mentioned earlier indicates that not only are financial incentives less preferred, they also tend to elicit a negative reaction from a sizable group of individuals. Comments such as "...it puts a price on your relative", "I don't like any of these, people are going to either want to help or not", as well as "I never thought in terms of getting paid because it's a mother," often followed the refusal to rank the economic programs. Only 74 percent of the respondents completed the entire section on economic incentives; 16 percent agreed to rank only some of these programs and the remaining 10 percent totally refused to consider any of them.

This is even more striking when one considers that the interview in its entirety deals with extremely sensitive material concerning family stress and the quality of familial relationships. In no other section was this refusal rate even approximated. Nor were such unusual objections voiced when families were asked to rank service programs, where only 1 percent refused to consider the entire section, 11 percent agreed to some of the rankings and 88 percent completed the entire section.

Given that more than one-fourth of the sample refused to rank some or all of the economic programs, we explored the data to see if variables could be identified which differentiated this group from the remaining caregivers. Those who refused were more likely to be the least educated, have the lowest income, live with their aged relative rather than in a separate household, be 65 years of age or over and the spouse of the aged person. In short, those who might need financial aid programs the most, are more likely to reject them (Table 3).

Obviously, these independent variables are interrelated in that they tend to define the circumstances of the spouse who is providing care for an impaired husband or wife. Therefore, we looked separately at the two groups of nonspouse caregivers, those who were adult children (n=131) and those who were otherwise related (n=53) to the aged relative. Among the adult children, refusal to rank the economic programs remained significantly associated with age, with the youngest offspring least likely to reject the economic programs out-of-hand. Among the other relatives, refusal to respond to the economic incentives was significantly associated with lower income. There was a strong trend (although not statistically significant) regarding age, with aged caregiving relatives more likely to refuse to rank these programs. In short, there does appear to be both a cohort and a class difference which may be attributed to a stronger adherence to familial independence and thus, a concurrent rejection of programs which imply an ideology of cash for care.

**Table 3**

**Percent refusing to respond to economic incentive questions, by selected variables**

| Variables | Total sample | Adult children only | Other relatives only |
|---|---|---|---|
| | | Percent | |
| **Relationship** | | | |
| Spouse | 73.7 | — | — |
| Child | 18.3 | — | — |
| Other Relative | 26.4 | — | — |
| ($x^2$) | [3](26.7) | — | — |
| **Age** | | | |
| Under 45 years | 4.7 | 3.0 | 10.0 |
| 45-64 years | 25.7 | 24.1 | 27.3 |
| 65 years or over | 44.7 | 18.2 | 33.3 |
| ($x^2$) | [3](18.9) | [1](7.1) | (1.9) |
| **Marital status** | | | |
| Never married | 4.8 | .0 | 16.7 |
| Married | 26.4 | 18.7 | 14.8 |
| Widowed | 26.1 | 14.3 | 44.4 |
| Divorced/ separated | 34.2 | 29.6 | 45.5 |
| ($x^2$) | (6.3) | (5.8) | (5.7) |
| **Caregiver's sex** | | | |
| Male | 25.0 | 18.7 | 16.7 |
| Female | 25.8 | 18.2 | 27.7 |
| ($x^2$) | (.0) | (.0) | (.01) |
| **Aged person's sex** | | | |
| Male | 35.0 | 5.3 | 37.5 |
| Female | 23.3 | 20.5 | 24.4 |
| ($x^2$) | (1.7) | (1.6) | (.11) |
| **Living arrangements** | | | |
| Same household | 38.7 | 17.1 | 50.0 |
| Separate household | 19.9 | 18.8 | 22.2 |
| ($x^2$) | [2](7.1) | (.0) | (1.5) |
| **Race** | | | |
| White | 28.2 | 19.2 | 23.3 |
| Black | 20.9 | 18.5 | 26.7 |
| Hispanic | 21.2 | 13.0 | 37.5 |
| ($x^2$) | (1.3) | (.5) | (.7) |
| **Employment status** | | | |
| Full-time | 20.4 | 19.7 | 20.0 |
| Part-time | 26.3 | 8.3 | 40.0 |
| Not employed | 31.4 | 18.6 | 28.6 |
| ($x^2$) | (2.9) | (.9) | (1.0) |
| **Yearly income** | | | |
| Less than $9,000 | 35.0 | 16.7 | 47.4 |
| $9,000 - $19,999 | 15.0 | 14.3 | 6.7 |
| $20,000 or more | 17.6 | 17.6 | 17.6 |
| ($x^2$) | [1](8.3) | (.2) | [1](8.1) |
| **Education** | | | |
| Less than high school | 38.2 | 24.0 | 33.3 |
| High school graduate | 21.0 | 17.1 | 19.0 |
| College graduate | 19.0 | 16.7 | 27.3 |
| ($x^2$) | [1](6.8) | (.7) | (1.0) |

## Economic versus service incentives

Even in light of the high refusal rate noted for the economic incentives, it must be stressed that our sample of caregivers did not reject interventions supportive of families caring for aged relatives. When asked to select the one program they liked best, 98 percent did so, and as mentioned earlier, 80 percent selected a service support. The next stage of our analysis sought to identify the variables associated with the choice of an economic versus a social support. Was there a subgroup of caregivers for whom one type of support was more appropriate than the other? (Tables 4 and 5).

The analysis indicated that the respondent's background characteristics were not critical in differentiating caregivers who selected either a service or an economic incentive.

**Table 4**

**Type of incentive preferred, by sociodemographic characteristics**

| Variables | Preferred program: Economic | Service | (n) | $x^2$ |
|---|---|---|---|---|
| | Percent | | | |
| **Relationship** | | | | |
| Spouse | 26.3 | 73.7 | (19) | .6 |
| Adult child | 20.2 | 79.8 | (19) | |
| Other relative | 18.0 | 82.0 | (50) | |
| **Age** | | | | |
| Under 45 years | 23.3 | 76.7 | (43) | 1.2 |
| 45-64 years | 17.4 | 82.6 | (109) | |
| 65 years or over | 23.9 | 76.1 | (46) | |
| **Marital status** | | | | |
| Never married | 28.6 | 71.4 | (21) | 1.3 |
| Married | 18.6 | 81.4 | (118) | |
| Widowed | 17.4 | 82.6 | (23) | |
| Divorced/separated | 22.2 | 77.8 | (36) | |
| **Sex of caregiver** | | | | |
| Male | 18.6 | 81.4 | (43) | .01 |
| Female | 20.6 | 79.4 | (155) | |
| **Race** | | | | |
| White | 17.5 | 82.5 | (120) | 3.2 |
| Black | 30.2 | 69.8 | (43) | |
| Hispanic | 18.8 | 81.3 | (32) | |
| **Family income** | | | | |
| Less than $9,000 | 27.1 | 72.9 | (59) | 2.7 |
| $9,000 to $19,999 | 15.0 | 85.0 | (60) | |
| $20,000 or more | 20.3 | 79.7 | (64) | |

However, two significant relationships did emerge within the second category of variables — those that defined the current caregiving experience. Where the aged relative was male, 36 percent of the caregivers chose an economic rather than a service support compared with 16 percent who did so when the relative was female. It appears that caregiving relatives are relatively more open to economic incentives when they are providing assistance to an aged male relative.

The only other variable showing a significant relationship with preference for type of incentive was current service utilization. The more the aged relative utilized home-delivered services, the more likely the family caregiver would prefer a service support. This suggests that actual experience with service supports has been positive for family members. Once received, families are more likely to be aware of the benefit and/or relief they provide.

**Table 5**

**Type of incentive preferred, by variables defining caregiving experience**

| Variables | Type of incentive: Economic | Service | (n) | $x^2$/t-score |
|---|---|---|---|---|
| | Percent | | | |
| **Older person's sex** | | | | |
| Male | 35.9 | 64.1 | (39) | [1]6.3 |
| Female | 16.4 | 83.6 | (159) | |
| **Caregiver's employment status** | | | | |
| Full-time | 17.7 | 82.3 | (96) | 2.8 |
| Part-time | 10.5 | 89.5 | (19) | |
| Not working | 25.3 | 74.7 | (83) | |
| **Living arrangements** | | | | |
| Same household | 28.3 | 71.7 | (60) | 2.8 |
| Separate household | 16.7 | 83.3 | (138) | |
| **ADL scale score (x)** | 16.8 | 14.7 | (198) | 1.7 |
| **Caregiving involvement scale score (x)** | 24.3 | 23.0 | (198) | .8 |
| **Caregiving consequences scale score (x)** | 8.6 | 9.1 | (196) | - .5 |
| **In-home service utilization index (x)** | 3.0 | 4.0 | (197) | [1]-2.2 |
| **Community-based service utilization index (x)** | 3.0 | 3.9 | (198) | -1.4 |

## Summary and conclusions

In summary, this research examined preferences for social and economic supports among a sample of 203 family members currently providing care for a frail aged relative. The study found that overwhelming majority preferred service programs, primarily homemaking and medical care, to financial incentives. Furthermore, a significant minority refused to even consider economic supports in reference to their personal situation. The aged person's sex as well as current levels of service utilization were associated with a preference for service over economic supports.

These findings have direct relevance for upcoming policy decisions. On the most basic level, we must advocate that the preferences of potential recipients deserve to be taken into consideration in the formulation of public programs and policies. Evidence from both this study and that conducted by Sussman clearly indicates that those families who currently confront the reality of caring for an aged relative prefer service over economic incentives if they are faced with a choice.

Yet, most of the current debate, as well as initiatives regarding family support, have focused on providing financial incentives for family care. In attempting to understand why this is so, as well as why families appear to have contrary preferences, we must look at the assumptions underlying such proposals and the available evidence relative to these same assumptions.

The basic underlying assumption behind programs which offer financial assistance to families is that the latter are faced with economic constraints which limit their ability to maintain their aged relative at home. Cash incentives are assumed to remove these barriers and induce families to provide home care to a frail relative. However, all available evidence contradicts these assumptions. The most recent studies have consistently found that of all types of stresses inherent in providing assistance, financial hardship is the least frequently reported by caregiving relatives (Cancer Care Inc., 1973; Cantor, 1980; Frankfather, et al, 1981; Simos, 1973). Findings from other aspects of our study are consistent with this conclusion. For example, only 3 percent of our sample identified financial assistance as the most critical help offered the aged relative; whereas 61 percent and 20 percent chose emotional and instrumental assistance, respectively. This is not to say that caregiving does not involve financial help nor entail economic costs to the family. Excluding the 19 spouses in our sample, 43 percent of the remaining caregivers helped their aged relative financially, and one-fourth of the total sample said that their family's financial situation had changed for the worse since having assumed the caregiving role. However, the strains associated with financial assistance do appear to be of lesser consequence when compared to the social and emotional impact of caregiving on the family. When asked what were the major problems they faced, only 4 percent spontaneously mentioned financial problems, whereas 64 percent mentioned at least one problem having an emotional component. Furthermore, only 3 percent identified financial assistance as the most difficult caregiving task. In summary, the available evidence indicates that the financial aspects of caregiving are not perceived as the most stressful by family members.

Furthermore, there is little empirical support for assuming that cash payments would induce an otherwise reluctant family to share its home with an aged relative (Prager, 1978). The majority of families respond voluntarily to the needs of their aged members to the best of their capabilities. As Sussman, (1977) concludes, "[a]t best, incentives facilitate the process and make it easier for the already committed and do little to change the minds of the refusers." The use of the word "incentives" itself, is therefore, a misnomer. The terminology implies that, by offering such programs, families will behave in ways which they would not have in their absence. The target population of a program under this heading would be the minority of families who reject their caregiving role and the success of such a program would be questionable.

Programs as described in this article act not so much as enticements as they do act as supports which maximize and, hopefully, prolong family efforts. From the families point of view, service, rather than financial supports best meet this goal.

While the general argument advanced in this paper has been in favor of expanded social and health care services, as a final note, it must be clearly stated that we do not question that financial support would be of benefit to many families and that most families would not reject the support if offered. If this were the best of all possible worlds, we would be advocating that both economic and service supports be made available, but this is not the situation. Current budget constraints only promise to get worse and choices are inevitable when resources are limited.

# Technical Note A

## Description of measures[1]

### Activities of daily living

The activities of daily living mesure used was a modification of the scale included in the Older Americans Resource and Services Project Multidimensional Functional Assessment Questionnaire. Respondents were asked whether their aged relative could perform each of 15 tasks (i.e., use telephone, shop, feed self, dress, bathe, prepare meals, etc.) with no, some, or great difficulty. Scores ranged from 0 to 30 with a mean of 15.1 and a standard deviation of 7.1. The scale alpha was .91.

[1]For detailed documentation of the specific item wordings, scoring procedures and psychmetric properties of this, as well as other scales described in this paper, see; *The Role of Families in Providing Long-Term Care to the Frail Elderly: Methodological Report #1* (August, 1982), available from the Brookdale Center on Aging of Huntger College, New York, N.Y.

**Service utilization**

Two indexes were constructed to measure the extent of current service utilization. The In-Home Service Index tapped the extent to which the aged relative used the following services (measured on a 5-point scale from never to daily use): homemaker, home health aide, visiting nurse, meals-on-wheels, and friendly visitor. Scale scores ranged from 0 to 11 with a mean of 3.8 and a standard deviation of 2.6. The Community-Based Service Index was based on the following eight services: counseling, transportation, information and referral, physical therapy, speech therapy, congregate meals, senior center, and financial management services. Scores ranged from 0 to 18 with a mean of 3.7 and a standard deviation of 4.0.

**Caregiving involvement**

Caregiving involvement was operationalized by a 12-item scale tapping the frequency of telephone contact, the frequency of face-to-face interaction, and the extent to which assistance was provided with: transportation, homemaking, shopping, meal preparation, personal care, health care, financial management, linkage with formal services, emotional support, and financial assistance. Scores ranged from 0 to 43 with a mean of 23.2 and a standard deviation of 8.9. Cronbach's alpha for this scale was .82.

**Caregiving consequences**

Caregiving stress was measured utilizing the responses to several open-ended and fixed-choice items. Respondents were asked to describe the major problems they have faced, the positive aspects of providing care; whether there was anything they were no longer able to do because of caregiving duties; whether they felt responsibilities to other family members were being neglected; and the extent to which they believed caregiving entailed sacrifices. Furthermore, respondents were asked whether providing care resulted in change in 17 specific areas including: work performance, recreation, their own physical and mental health, finances, relations with other family members, plans for the future as well as feelings towards their own aging. Scores on this 29-item scale ranged from 0 to 24 with a mean of 9.8 and a standard deviation 6.1. The alpha coefficient was .88.

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