

Respite care: Lessons from a controlled design study

by Rhonda J. V. Montgomery

Findings are reported from a study of respite services in which an experimental design was used to assess the impact of respite on families caring for elderly persons. Almost one-third of the 189 families eligible for respite services offered through Medicare waivers failed to use any services. The majority of families chose respite services in their home for

frequent periods of 3 hours. Families spent, on average, only 63 percent of their allotted funds. Respite services appeared to delay nursing home placement among families with adult children as caregivers but encouraged placement when spouses were the primary caregivers.

Introduction

Respite care is a relatively new concept that includes a wide range of services intended to give temporary relief to families caring for disabled members. The development of respite services in the United States accompanied the deinstitutionalization movement for mentally and developmentally disabled persons (Cohen and Warren, 1985). As growing numbers of parents of disabled children experienced the burden of continuous caregiving, they began to seek and develop respite programs. Recognition of the parallel need for relief of family members caring for frail and disabled elderly persons has been even more recent in the United States. Although there is some indication in the literature that respite has been provided in many communities on an informal basis, formal respite services for the elderly are quite new and not widely available. Still, respite services continue to be among the most widely advocated forms of support for families assisting impaired elders in their homes. Both practitioners and researchers have suggested that respite care can relieve the burden of the caregiving situation and, perhaps, even allow families to continue to care for elders who would otherwise have been placed in a nursing home (Brody, 1985; Doty, 1986; Pratt et al., 1985; Scharlach and Frenzel, 1986; Zarit, Todd, and Zarit, 1986). Despite this belief in the benefits of respite, information about respite, particularly the impact of these services on families, is limited, widely scattered, and often difficult to obtain.

One of the difficulties in assessing respite is the multitude of forms that respite services can assume. The defining characteristic of a respite service is the purpose for which it is delivered, i.e., to provide a rest for caregivers (Montgomery, 1986). Respite services can be delivered in the home of a client, in a group setting, or in an institution. Home health care, chore services, companion services, adult day care centers, and nursing home services can be considered respite if they are offered for the purpose of providing the primary caregiver relief from his or her caregiving tasks.

This research was supported by the Health Care Financing Administration Contract No. 95-C-98281 with the University of Washington Institute on Aging.

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A more difficult barrier to the assessment of the impact of respite has been the absence of controlled design studies. Several researchers have reported perceived benefits of respite and information about caregiver satisfaction with services. (In-depth reviews can be found in Stone, 1985, and Montgomery, to be published.) However, in no study to date has the impact of respite on caregiving behavior been documented.

This article contains findings regarding respite services that were obtained from a study in which an experimental design was used to assess the impact of support services on families who were caring for an older impaired member. Specifically, attention is given to patterns of respite use, preferences of caregivers for different types of respite service, and the impact of respite on caregiver burden and on nursing home placement.

Methods

Study design

The study, conducted from 1983 through 1987, included 541 family units consisting of an impaired elder and at least one family member who was providing regular care or assistance to the elder. The families were self-referred to the project, having obtained knowledge of the services from social or health service agencies and/or through mass media advertisements and stories. The majority of families first learned of the services through newspaper articles or television public service announcements. To be eligible for the study, the impaired person had to be noninstitutionalized and reside within King County, Washington, and the family member had to live within a 1-hour driving distance of the older person.

Each family was randomly assigned to one of five treatment programs or to the control group. The five treatments were family support programs consisting of various combinations of education and respite services. Of interest here are families in the control group; families in the first treatment group, who were eligible for all project services; and families in the fifth treatment group, who were eligible only for respite.

The respite services were provided to eligible families on a fee-for-service basis. Medicare waivers

were used to provide each eligible family with up to \$882 worth of free respite services over a 12-month period. This dollar amount was equivalent to the cost of 14 days of respite care in an institutional setting. Families were able to choose from among three types of respite settings. Respite was available in the home either for short daytime periods or overnight. Respite was also available through three adult day care centers and in a nursing home setting. The intent of the project was to give families flexibility and choice in their use of respite services. Families were able to use their allotted Medicare funds to buy services from any of the participating providers in any combination.

Measures

Data were obtained through interviews conducted with the impaired persons (when possible) and their caregivers. Subjects were interviewed three times. Interviews were conducted before the family units were assigned to one of five treatment groups (T1), after 12 months of service eligibility (T2), and again 20 months after the initial interview (T3).

In addition to basic demographic information, data were collected concerning the elderly person's level of disability, family structure, use of community services, quality of family relationships, and morale. More than one-half of the elders were able to participate in the initial interviews. Information on the remaining 269 elders was collected from family caregivers.

The caregivers were asked about their family structure, the types of tasks they perform, the amount of time they spend performing tasks, the extent to which they find caregiving burdensome, the quality of their relationship with their elderly relative, their morale, and their satisfaction with services provided through the project.

In addition to data collected through interviews, records were kept concerning the utilization of all project services.

Sample characteristics

Because 35 of the families included in the study had two impaired elders, the sample included 576 elders. The median age of the elders was 81.6 years. One-third (33 percent) were male and 67 percent were female. Forty percent of the elderly persons were married and 52 percent were widowed. Many of the elders were isolated, with 22 percent indicating that they had no informal contact with persons other than their immediate families.

The majority of elders had attended high school: 15 percent had some high school education, 20 percent had completed high school, and 35 percent had attended some post-high-school training program or college. The primary source of income for 74 percent of the elders was social security, and the median income for elders was \$7,500. The majority of the elders (57 percent) reported their health to be "fair" or "not good at all," and 28 percent of the elders

were reported to have a serious mental impairment.

The 541 primary caregivers were relatives who considered themselves to have the primary responsibility for attending to the elders' needs. Approximately 31 percent (167) were the spouse of the elder and 59.3 percent (321) were adult children. All of the spouse caregivers and 64 percent of the caregivers who were adult children resided in the same household as the elder. Consistent with findings in the literature, the majority of the primary caregivers (79 percent) were female. Most of the caregivers (84.5 percent) reported their health to be good, very good, or perfect. Forty percent of the caregivers were employed full time (155) or part time (62). The median household income for primary caregivers was \$17,500, and the primary sources of income were their own or a spouse's current job (51 percent) or social security (29 percent).

Primary caregivers reported assisting elders with all aspects of their daily living. Caregivers devoted an average of 8 hours per week to personal care tasks, 15 hours per week to assistance with household tasks, 3 hours per week to business matters, and 7 hours per week to transportation and errands.

Findings

Patterns of use

A total of 189 caregivers were eligible for respite services. According to the project records, 100 of these caregivers used in-home respite care (29 using in-home respite at night); 16 used respite in an adult day care center; and 18 used respite in an institution. Twelve caregivers used more than one type of respite. Seventy caregivers wanted no respite, and in some cases the elder died before the family was able to receive services. In total, 122 caregivers, or 64.6 percent of those eligible, were provided respite. The average number of hours used for in-home care was 3.32 per visit; that for adult day care was 5.0 hours, the maximum allowed per day. The median number of visits was 21 for elders with spouse caregivers and 16 for elders with an adult child as the caregiver. The average number of days in a nursing home was 8.4 per placement.

A detailed study of patterns of use revealed that in-home respite was the form of respite most preferred, independent of the relationship of the caregiver to the elder (i.e., spouse or child). Of the 43 spouses who obtained respite for their elder, 35 (81 percent) used only in-home respite services. Of the 73 adult children who obtained respite services for their parents, 50 (68 percent) used only in-home services. Although the differences in patterns of respite use between spouse and child caregivers were not statistically significant, a higher proportion of adult children (11 caregivers, or 15 percent) than spouses (1 caregiver, or 2 percent) used the nursing home as the only source of respite. Adult day care accounted for about 7 percent of respite services used by all caregivers, and a combination of service use

accounted for about 10 percent of all respite service use. When multiple forms of respite were used, caregivers most often chose in-home respite in combination with adult day care (six caregivers) or nursing home services (five caregivers). The amount of funds spent for each respite form did not vary significantly, although the mean cost for nursing home services (\$703) was slightly higher than the cost for the other services (\$560 for in-home services and \$538 for adult day care). Persons using a combination of services had the highest average cost (\$793).

Perhaps the most interesting facts about the use of respite services are those concerning nonuse of services. Of the 189 elders eligible to receive services, 36 percent did not use any. Furthermore, for those who used the services available, the average amount of dollars spent was only 63 percent of that for which they were eligible. The amount of money spent by adult children (\$610) differed little from the amount spent by spouses (\$591).

It is equally important to note that families providing care for 20 of the elders used more funds for respite than were available through the project. These families paid an average of \$183 in out-of-pocket costs for additional respite services.

In the analyses of data, no patterns in the type of respite services used that were related to the income level of the elder or to that of the caregiver were revealed. Elders who used the respite services of a nursing home were found to have higher disability scores, as measured by activities of daily living, than those using other forms of respite had. When health level was measured by a single-item self-report measure, elders using adult day care were reported to be healthier than those using either nursing home respite or in-home respite were.

Approximately 25 percent of the sample for this study consisted of families caring for elders with Alzheimer's disease. Therefore, separate analyses for this group were performed to learn more about their differences from and similarities to caregivers of elders impaired by other diseases and disabilities. The pattern of service use for caregivers of Alzheimer's patients did not vary significantly from that of other caregivers. However, some minor differences were found. A slightly higher proportion of caregivers of Alzheimer's patients attended the caregiver seminars (71 percent versus 66 percent), and a slightly lower percentage of these eligible families used respite services (60 percent versus 70 percent).

Satisfaction and preferences

Regardless of the form of respite used, the overwhelming majority of participants indicated that they were satisfied or very satisfied with the services (73 percent using nursing home services, 80 percent using in-home services, and 88 percent using adult day care services). In addition to being asked about their use of and satisfaction with project services, caregivers were asked about their preferences for support services. Participants were asked whether they

would have liked to have used any of the services offered to other treatment groups during the past year. Almost one-half of the participants in both the control group and the group offered respite services only expressed a desire to use all of the educational services. In some cases, these participants had located support groups or participated in seminars offered through other programs and expressed desire for greater participation.

To examine their desire for respite services, caregivers not assigned to the respite program were asked which types of respite they would have liked. The most desired form of respite, which was chosen by more than 56 percent of the respondents, was in-home, respite for short periods (4-5 hours). A large number of caregivers also expressed a desire for overnight respite in their homes (48 percent). Fewer expressed a desire for respite in an adult day care center (28 percent) or an institution (24 percent). Treatment groups did not differ in their preferences for respite services.

Finally, caregivers were asked about other services in the community that they would have liked to use. It is not surprising that the services most frequently desired are chore services (41.4 percent) and home health services (37.7 percent), because these services often are used as respite for the caregiver.

Impact on burden

One of the central research questions of the project concerned the impact of services on the burden that caregivers experienced. Consistent with earlier work of the author (Montgomery, Gonyea, and Hooyma, 1985), a distinction was made in this study between objective and subjective burden. The concrete events, happenings, and activities resulting from caregiving were separated from feelings, attitudes, and emotions expressed about the experience. Objective burden was defined as the extent of disruption or change in various tangible aspects of the caregiver's life and household because of caring for the elderly person. Subjective burden was defined as the extent of perceived change in psychological aspects of stress because of caregiving. A 10-item, 5-point scale was used to measure the burden of caregiving. Caregivers were asked whether various aspects of their lives had changed during the past year as a result of caregiving. A caregiver's subjective burden score is an additive score that includes stress in the relationship, whether the caregiver feels manipulated by the care receiver, nervousness and depression, and a perception of care receivers as overly demanding. A caregiver's objective burden score is the sum of scores for time to oneself, time available for recreation and vacation, time for own work, and time for friends and relatives.

Analysis of variance with repeated measures was used to determine whether the level of caregiver burden was significantly different for caregivers eligible for respite than for caregivers in the control group. No differences between the groups in the level of objective or subjective burden were revealed at T2.

However, in analyses restricted to caregivers assisting elders who continued to reside in the community (excluding those living in a nursing home), a reduction in subjective burden was found. The difference was statistically significant for the treatment groups but not for the control group (Table 1). This pattern was not repeated for the data collected at T3.

Impact on nursing home placement

Monetary savings resulting from delay or prevention of institutionalization has been one of the anticipated benefits of respite care. To test for such delay or prevention of nursing home placement, a series of multiple analyses of variance were performed. (A detailed report can be found in Montgomery and Borgatta, 1987.) The first set of analyses was used to determine whether there were differences between the treatment groups and the control group in the number of months that elders resided in a nursing home during the first 12-month period of the project. These analyses were repeated for the 20-month period followup data. In addition to testing for direct effects of the two treatment groups, analyses were conducted to test for interaction effects related to the level of the elder's health, the elder's income, and the relationship of the caregiver to the elder (spouse or child). No direct effects were found initially, nor were interaction effects found for the level of elder's health or income. When the variable of the generation of the caregiver was entered into the analyses, an interaction effect was revealed. This prompted separate analyses for the samples of spouse caregivers and of adult children caregivers.

As revealed in Tables 2 and 3, the findings for the two subsamples were substantially different. In the case of spouse caregivers, elders in the treatment groups used more months of nursing home services than did elders in the control group. This was true for both the T2 data and T3 data, and the differences were statistically significant ($T = 2.22, p \leq .05$). In contrast, for the sample with adult children as caregivers, elders assigned to the treatment groups used fewer months of service than did those in the

control group, although the differences were not statistically significant.

To enhance understanding of the events and the impacts of the treatment groups on caregiving behavior, a second series of analyses were performed that included only persons who used at least 1 month of nursing home service. This was done because of the relative rarity of nursing home placement for all of the groups. Because a majority of the families reported no use of nursing home services, the dependent variable was highly skewed toward zero. This secondary analysis revealed patterns that paralleled those found in the initial set of analyses. Families in the control group with spouses as caregivers used fewer months of service than those in the treatment groups did; families in the control group with children as caregivers used more months of service than those in the treatment groups did. These differences were statistically significant.

Significant differences in nursing home use were not found between the two treatment groups (i.e., respite only and respite with education services) for spouse caregivers. However, when the caregiver was an adult child, those eligible for both education and respite reported a higher number of months in the nursing home than did those eligible for respite only. Hence, the educational component of the intervention, like the respite service, appears to have affected spouse caregivers differently from caregivers who were adult children.

Discussion

One of the most important findings of the project is that families who are caring for elders in the community are difficult to reach and resistant to using services. Even after agreeing to participate in the project, almost one-third of the families eligible for respite did not use any services, although all services were offered free of charge. Furthermore, on the average, those families who did use the respite services used less than two-thirds of the funds for which they were eligible. This finding raises some questions about the validity of the prevalent belief of policymakers and practitioners in the "woodwork effect," the notion that new support services for families will create demand. Certainly the families participating in this study did not display a pattern of overuse, nor did they use respite simply because the service was available. It is more likely that efforts of future programs to reduce burden, delay nursing home placement, and reduce costs will be unsuccessful because eligible families cannot be located sufficiently early in their caregiving roles to have an effect on future behavior. It is clear from the relatively homogeneous demographic characteristics of the sample that families who are likely to use support services are not representative of the full range of families confronting the caregiving situation.

A second conclusion to be reached from the study underscores findings of other studies in which the preference of the majority of caregivers for frequent

Table 1

Analysis of variance with repeated measures on subjective burden for caregivers of elderly persons living in the community from T1 to T2, by service group: King County, Washington, 1983-87

Service group	Sums of squares	Degrees of freedom	F value
Education program and respite	187.69	1	122.9
Control	9.14	1	1.4
Respite only	127.21	1	123.7

¹ $p < .05$.

NOTE: T1 is interview before services were made available. T2 is interview 12 months after services were made available.

SOURCE: (Montgomery and Borgatta, 1987).

short-term respite in the home was noted (New York State Department of Social Services, 1985; Connecticut Department of Health Services, 1985; Washington State Department of Social and Health Services, 1986). From both the patterns of respite use and the stated preferences of participants, it is clear that the majority of caregivers prefer short-term in-home respite services. This form of respite not only provided much needed time to attend to shopping errands and medical appointments but was also easier to use. The preparations necessary to transport an elder to another setting were often viewed as formidable. Indeed, some caregivers indicated that respite out of the home really did not provide the caregiver with rest. Additionally, the assistance that respite workers provided with household tasks while attending to the needs of elders was noted as an advantage of in-home respite. However, the data do suggest that a variety of services are needed and that families should be able to choose a service in keeping with personal needs.

Finally, the results of the study once again underscore the differences in the situations of caregivers who are spouses and those who are adult children. Although differences in caregiving activities have been noted in previous studies (Doty, 1986; Horowitz, 1985), the findings reported here point to differences in caregiving situations.

Spouses tend to care for older, less healthy elders than adult children do. In the absence of intervention procedures, they will continue to provide extensive and time-demanding care for their impaired spouse

while reporting levels of burden that are no different from those reported by children. Spouses tend to resist nursing home placement at all costs.

Adult children, on the other hand, tend to engage in caregiving tasks that require less hands-on care and fewer hours of service. In the absence of interventions, they are likely to place their parent in a nursing home when the parent begins to require extensive personal care; that is, children end their caregiving careers at about the time that spouses begin identifying themselves as caregivers. It is this basic difference in caregiving patterns that likely accounts for the differential impacts of respite on spouses as opposed to children.

Respite services appear to alter adult children's behavior by delaying nursing home placement. Although the data do not support the conclusion that the treatments altered the number of nursing home placements of elders cared for by children, they do suggest that the families in the treatment groups used fewer months of nursing home service when they did place their elder than did persons in the control group.

In contrast, the data suggest that respite services encourage spouses to place elders in nursing homes. Given the strong resistance to nursing home placement that is found among spouses and the taxing nature of their caregiving tasks, this finding could be viewed as encouraging because it might reflect more appropriate use of available services. The finding also means that future studies should be focused on the issue of quality of care for homebound elders. The

Table 2

Mean number of months spent in nursing homes by elderly persons with spouse caregivers at T2 and T3, by service group: King County, Washington, 1983-87

Service group	T2			T3		
	Number in sample	Mean months in nursing home	Standard deviation	Number in sample	Mean months in nursing home	Standard deviation
Education program and respite	36	1.69	3.26	35	3.58	6.22
Respite only	30	2.47	4.25	29	4.10	6.55
Control	17	.06	.24	15	.13	.35

NOTE: T2 is interview 12 months after services were made available. T3 is interview 20 months after services were made available.

SOURCE: (Montgomery and Borgatta, 1987).

Table 3

Mean number of months spent in nursing homes by elderly persons with adult child caregivers at T2 and T3, by service group: King County, Washington, 1983-87

Service group	T2			T3		
	Number in sample	Mean months in nursing home	Standard deviation	Number in sample	Mean months in nursing home	Standard deviation
Education program and respite	53	1.24	2.85	51	2.74	5.09
Respite only	64	.94	2.51	53	2.19	4.67
Control	69	1.65	3.52	69	3.54	6.45

NOTE: T2 is interview 12 months after services were made available. T3 is interview 20 months after services were made available.

SOURCE: (Montgomery and Borgatta, 1987).

combination of spouse resistance to nursing home placement and intense hands-on care tasks should prompt some concern.

Because the data suggest opposing outcomes for adult child caregivers and spouse caregivers, it might be concluded that the overall costs and benefits offset one another and therefore make little difference. Although the conclusion that services lead to cost savings is not warranted, a conclusion that they make no difference is equally inappropriate. The findings suggest that respite care leads to more appropriate use of services for both spouses and children, which can easily translate into human benefits despite any lack of cost savings. The fact that this pattern persists from the 12-month followup to the 20-month followup suggests that the impact of the respite services is not just short term. Rather, the support strategies appear to influence caregiving behavior over an extended period of time.

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