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ABSTRACT

Studies consistently have found that caregivers who use respite care are satisfied with and appreciate such care. However, preliminary evaluations of the effect of respite care on caregiver burden have had mixed, limited, and in some cases null empirical findings of program effectiveness. This study explored the relationship between caregiver characteristics and utilization of respite care in order to understand the caregivers' perceptions of burden and social support as well as their need for formal support services. Subjects included 22 caregivers using respite care for families with dementing relatives and 26 demographically matched caregivers not using respite care. Also included were 43 caregivers of mentally or physically disabled children using the in-home respite care program. Subjects responded to a questionnaire focusing on caregiver demographics, length of care, sources and availability of social supports, and attitudes toward and utilization of respite care. Results indicated that caregivers who used the respite care perceived a higher level of burden than did non- users. While differences in burden could be due to varying degrees of physical, cognitive, or behavioral problems that drive caregivers to seek respite, examination of severity, mental status, and prescription of behavioral management medications revealed no differences in the patient samples. (ABL)

RESPITE CARE FOR IMPAIRED FAMILY MEMBERS: AN EXAMINATION OF TWO AGENCIES

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ABSTRACT

This study explores the relationship between caregiver characteristics and utilization of respite care in order to understand their perceptions of burden and social support as well as need for formal support services. In addition, in order to generalize the concept of burden and further understand the role of respite care, we also obtained a convenience sample of caregivers of mentally (or physically) impaired children.

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> "There should be more persons to help people like me. There isn't enough people in the area in which I live. There is only one, and she is thinking of starting a different and new job. That scares me because I really need the time--and more, sometimes. I pay her an extra $5.00 for gas just so she will come. I can't really afford it, but if I don't get away I'll go crazy. Thank you."
>
> ...a parent of a mentally impaired child

Although intuitively appealing, scientific and programmatic support for respite care has been severely eroded by mixed, limited, and in some cases null empirical findings of program effectiveness (e.g., Burdz, Eaton & Bond, 1988, and Lawton, Brody & Saperstein, 1989). However, these studies consistently find caregivers who use respite are satisfied with and appreciate respite care. Such preliminary evaluations of the effect of respite care on caregivers burden, especially when produced from experimental designs of program effectiveness, lead some policy makers to the conclusion that respite care has no impact and should not be publically supported (Callahan, 1989). With such strong face validity, why doesn't respite care affect caregivers' perception of burden?

This study explores the relationship between caregiver characteristics and utilization of respite care in order to understand their perceptions of burden and social support as well as need for formal support services. In addition, in order to generalize the concept of burden and further understand the role of respite care, we also obtained a convenience sample of caregivers of mentally (or physically) impaired children.

<u>Background</u>. In a survey of 150 caregivers using an VA-based respite service, Scharlach & Frenzel (1986) found that respite helped them to feel mentally and physically better, improved their relationships, and increase their confidence in the caregiver role. In a survey of 2,362 family caregivers of dementia patients, Caserta and his colleagues (Caserta, Lund, Wright, & [illegible]burn, 1987) found that those respite nonusers who claimed they were not yet ready to utilize formal support services had less burden and more social support, as well as caring for younger and less impaired patients. Miller, Gulle & McCue (1986) found that of 18 families using institution-based respite, most expressed relief and gratitude and only 4 were uncomfortable relinquishing responsibility and control of their family member. Although these studies suggest that respite care benefits families, they lack comparison/control groups and appropriate measures of respite impact. Thus, these studies do not address the impact of respite care on caregivers.

Better controlled studies do not clearly support the impact of respite care. In a pretest-posttest design, Burdz, Eaton & Bond (1988) found that caregivers felt institution-based respite care improved dementia patients memory and social behavior and increased their quality of life, with a concomittant worsening in their situation and greater difficulties with the patient. They suggest that the contrast between the time spent in caregiving and respite made these families less willing to resume caregiving activities. Lawton, Brody & Saperstein (1989) in a pretest-posttest design with random assignment to treatment group support these findings, reporting that caregivers perceived burden remains unaffected; but [illegible] also report that use of respite care tends to extend the time families care for patients, delaying institutionalization by 22 days. An important caveat to the use of experimental designs is the assumption of homogeneous treatment implementation. This assumption is necessarily violated, especially in the case of caring for patients with irreversible dementias due to the different rates of disease progression and flucuating use of services as confounded with perceived burden. Since researchers can not control the effects of the intervention they can not reliably document differential impact of respite care on caregivers.

METHOD

Subjects. Twenty-two caregivers using respite services for families with dementing relatives in the Helping Hand program, an ADRDA-sponsored program in Lexington, Kentucky, and 26 demographically matched caregivers (of 40) not using respite who were selected from the patient registry of the referring memory disorders clinic, responded to surveys. Additionally, 43 (of 98) caregivers of mentally or physically disabled children utilizing the in-home respite care program provided by the Bluegrass Association of Retarded Citizens responded to surveys. Thus, the study design was quasi-experimental, using a mailed questionnaire with three groups.

The questionnaire focused on caregiver demographics, length of care, sources and availability of social supports, and attitudes toward and utilization of respite care. Two instruments were used as measures of caregiver burden and social support. The Burden Interview (Zarit et al., 1980) focused on objective and subjective factors influencing perceived burden. The Social Provision Scale (Russell & Cutrona, 1984; Blieszner & Mancini, 1985) assessed the quality of social relationships on six dimensions: attachment, integration, reliable alliances, available guidance, reassurance of self-worth, and opportunities for nurturance.

RESULTS

Descriptive analyses show that the majority of the 22 Helping Hand program caregivers and matched sample of 26 respite care non-users were characterized by married (90.9% and 84.6%), female (86.4% and 80.8%), and unemployed (81.8% and 61.5%) individuals. This was to be expected since the literature points out that many caregivers to older dementing family members are spouses. However, Helping Hand caregivers were statistically different in their educational attainment, with over a third with a high school education (36.4%) and half (50%) with some college or a college degree, compared to non-users of respite, 23.1% of whom had high school, 42.3% had some college or a college degree, and over a third (34.6%) had a graduate degree ($X^2(5)=21.67$, $p<.001$). Over half of Helping Hand family incomes ranged from $10,000 to $20,000 (57.9%), compared to 50% of the non-user sample who had incomes over $30,000 ($X^2(4)=13.30$, $p<.01$). Among the 43 caregivers of mentally or physically disabled children utilizing the in-home respite service program, mean age was 40.4 years, with the majority (83.7%) being female. Almost half the sample (44.2%) had a high school education and 51.2% had an annual income under $20,000. A significant difference for employment status emerged, with forty-four per cent working full-time and an additional 14.6% working part-time ($X^2(2)=9.44$, $p<.009$). Also of significance was marital status: a third of these caregivers were divorced, compared with 58.1% who were married ($X^2(3)=10.91$, $p<.01$). Finally, BGARC caregivers had significantly higher rates of responsibility to children ($X^2(2)=25.36$, $p<.000$). In general, compared to the other two groups, the caregiver sample utilizing the BGARC respite program were most likely to be female, single parents with young children, often working outside the home, with possibly inadequate incomes considering their overall familial obligations (Table 1).

Table 1. Demographic Characteristics

Demographic Variable	AD Respite Care Users %	AD Respite Care Non-Uers %	MR Respite Users %
Total Surveyed	22	26	43
(response rate)	95.7	66.7	43.9
Employment			
(not employed)	81.8	61.5	41.5^c
(full-time)	13.6	34.6	43.9
(part-time)	4.6	3.9	14.6
Sex			
(female)	86.4	80.8	83.7
Marital status			
(divorced)	-----	7.7	30.2^d
(married)	90.9	84.6	58.1
Years of education			
(< 12)	36.4^a	23.1^a	44.2
(13-14)	31.8	23.1	25.6
(15-16)	18.2	19.2	11.6
(17+)	13.6	34.6	18.6
Income levels			
($0-10,000)	31.6^b	7.7^b	18.6
($10-20,000)	26.3	19.2	32.6
($20-30,000)	21.1	23.1	25.6
($30-40,000)	21.1	7.7	9.3
($40,000+)	----	42.3	14.0
Other responsibilities			
(home)	75.0	66.7	11.9^e
(home and children)	20.0	33.3	83.3

[a] $X^2(5)=21.67$, $p<.001$
[b] $X^2(4)=13.30$, $p<.01$
[c] $X^2(2)=9.44$, $p<.009$
[d] $X^2(3)=10.91$, $p<.01$
[e] $X^2(2)=25.36$, $p<.000$

Daily hours spent in caregiving duties did not vary significantly among the three groups, whereas perceptions of burden was significantly lower among non-users of respite care (mean score of 54.04, sd=15.57) than among Helping Hand respondents (mean score=64.47, sd=13.55, t(41)=2.31, p<.03) (Table 2).

Table 2. Mean Caregivers' Perceived Burden*
(with s.d.'s in parentheses)

	AD Respite Care		MR Respite
	Users	Non-Uers	Users
Daily hours spent in caregiving duties	15.58 (11.11) 20	9.62 (8.72) 21	12.87 (8.03) 41
Perceptions of Burden	64.47^a (13.55) 19	54.04^a (15.57) 24	57.46 (20.69) 35

* 15 items (modified Zarit et al., 1980)

^{a} t(41)=2.31, p<.03

In terms of social support, no significant differences appeared among the three samples for total social support, whereas two of the six dimensions revealed significantly lower scores for Helping Hand caregivers compared to non-users of a respite care program. Specifically, the Helping Hand group felt less integrated (mean score=12.10, sd=2.32 versus 14.32, sd=2.19, t(41)=-3.23, p<.002), with less opportunity for nurturance (mean score=13.10, sd=2.32 versus mean score=14.60, sd=2.06, t(44)=-2.33, p<.02). These results suggest that respite users among caregivers to family members with dementia are more isolated than non-users, perhaps leading to their reliance on formal respite. These results also have implications for the personalized nature which formal respite care programs must assume if they are to address the particular needs of these families (Table 3).

Table 3. Mean Perceived Social Support

Dimension of Social Support	AD Respite Care		MR Respite
	Users	Non-Users	Users
Social attachment			
	12.35	13.32	11.23
	(2.62)	(3.04)	(3.41)
	20	25	40
Social integration			
	12.10[a]	14.32[a]	12.08
	(2.32)	(2.19)	(2.81)
	21	22	40
Reliable alliances			
	13.75	14.16	12.74
	(2.07)	(3.12)	(2.71)
	20	25	42
Guidance			
	13.00	13.56	12.31
	(2.07)	(3.10)	(2.47)
	21	25	39
Reassurance of worth			
	12.84	14.22	13.00
	(1.86)	(2.73)	(2.54)
	19	23	38
Opportunity for nurturance			
	13.10[b]	14.60[b]	13.76
	(2.32)	(2.06)	(2.23)
	21	25	42
Total social support			
	78.61	82.95	76.14
	(9.14)	(13.32)	(11.98)
	18	21	35

[a] $t(41)=-3.23$, $p<.002$
[b] $t(44)=-2.33$, $p<.02$

Finally, in terms of attitudes toward respite between the two groups utilizing formal respite services, Helping Hand families perceived significantly more benefit (mean score=3.35 on a 7-point scale, sd=.77) and satisfaction (mean score=2.94, sd=2.76) than did BGARC families (respectively, mean score=2.85, sd=2.71, $t(37)=10.79$, $p<.0001$; and mean score=1.28, sd=7.75, $t(34)=2.75$, $p<.009$) (Table 4).

Table 4. Utilization and Attitudes toward Respite Services

	AD Respite Care Users	MR Respite Users
Membership in other support organizations (none)	76.2%	81.4
Perceived benefit of respite care to caregiver families	3.35[a] (0.77) 20	2.85[c] (2.71) 39
Satisfaction with respite care in general	2.94[b] (2.76) 18	1.28[d] 7.75 36

[a] *t*(18)=17.12, *p*<.0001
[b] *t*(16)=7.52, *p*<.0001
[c] *t*(37)=10.79, *p*<.0001
[d] *t*(34)=2.75, *p*<.009

This may be due largely to the difference in program structure between Helping Hand and Bluegrass Association of Retarded Citizens. Helping Hand provides a group environment and sense of community among both its dementing participants and staff. Furthermore, participants are engaged in mentally and socially stimulating activities by program staff. On the other hand, BGARC care providers go individually to the homes of caregivers of mentally/physically disabled family members with the main purpose of providing company to the family member while the caregiver is away. Therefore, BGARC lacks the social involvement of participants with staff, and staff with families.

DISCUSSION

Not only did we fail to find that caregivers using respite services perceived less burden, we discovered a higher level of perceived burden. Differences in burden could be due to varying degrees of physical, cognitive, or behavioral problems that drive caregivers to seek respite. But examination of their severity, mental status, and prescription of behavioral management medications reveals no differences between the two patient samples. Differences in burden could also be attributable to pre-morbid caregiver responses to stressful situations. And although our results suggest that there are different levels of self-efficacy and self worth that are derived from social support, it does not directly address this explanation.

The results indicate that certain caregivers are more likely to avail themselves of respite programs. Caregivers of older dementing adults tend to have significantly lower socioeconomic status, higher levels of perceived burden, and lower levels of perceived social support, especially in terms of social integration and reassurances of self-worth. The higher levels of perceived burden and perceived lack of adequate support among respite users have implications for the personalized nature which formal respite care programs must assume if they are to address the particular needs of caregivers of family members with dementia. Finally, it is clear that respite users value and are satisfied with respite services.

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