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ABSTRACT

Research has found that approximately 80 percent of the care received by elderly people living at home is provided by family members. Although assistance provided by informal supports can be important in sustaining the functionally disabled elderly at home, caregiving can have important negative effects on the informal providers. To examine the relationship between informal caregiving and burden in a service-rich environment, the experiences of 1,068 functionally disabled older persons in New York City were studied for one year. Information was obtained on their living arrangements, on the nature and extent of their functional disabilities, and on the sources and extent of help they received. Data were collected from 422 informal caregivers on both caregiving effort and burden. Three aspects of burden were measured: employment, finances, and restrictions on personal life. Results showed major differences between caregivers living with the disabled older person and those living elswhere, both in intensity of reported help and burden. Caregivers living apart from the disabled older person offered about the same amount of help as those living with the disabled person. Increased help was associated with burden only for caregivers living with the impaired person. These results suggest a need for stronger service supports for informal caregivers living with those whom they help. (KGB)

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BURDEN EXPERIENCED BY INFORMAL PROVIDERS OF HOME CARE FOR THE ELDERLY

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INTRODUCTION

The extensive participation of informal supports in long-term care is well established [see, for example, Brody, Poulshock, and Masioccia (1978), Moroney (1977), Frankfather, Smith, and Caro (1981), Horowitz and Dobrof (1982) and Poulshock (1982)]. Perhaps best known is Shanas's (1979) finding that approximately 80 percent of the care received by elderly people living at home is provided by family members. The dominant role played by informal supports in long-term care poses complex issues for advocates of publicly subsidized home care. Under some circumstances the introduction of publicly-funded services can serve largely to replace care previously provided by informal supports. Some argue that publicly-funded home care should not substitute for informal support; it should not be introduced when it would lead to a reduction in effort on the part of informal supports. Others argue that informal care giving can pose a major burden for informal supports (Frankfather, Smith, Caro, 1981) and that a major immediate objective of organized services in long-term care is to relieve informal supports of unreasonable caregiving burden.

The purpose of the current paper is to examine the relationship between informal caregiving and burden in a service-rich environment. The data are drawn from a larger study concerned broadly with the impact of publicly-funded home care services in New York City. Particularly for those who are Medicaid eligible, New York City offers extensive organized home care to those with serious functional disabilities. In 1982 the home attendant program, the largest of the city's home care programs provided an average of over 50 hours a week of care to a caseload which averaged over 23,000. It should be noted that city policy calls for consideration of informal caregiving potential in authorizing services. Organized home care is to be introduced only to the extent that informal supports are unavailable to provide needed care.

METHODOLOGY

The study tracked the experiences of 1,068 functionally disabled older persons for a period of a year. Research subjects were recruited from among patients in six large general hospitals in New York City. The study was limited to patients of low and moderate income (up to 200 percent of SSI eligibility) and those expected to leave hospitals with a serious functional disability. All were interviewed while in the hospital. Those who went home were interviewed again four and twelve months after the end of acute care. For those who went home, an attempt was made also at the four month stage to interview an informal support. At the four month stage interviews were completed with 633 functionally disabled older persons and 422 informal supports. For two-thirds of the primary research subjects, therefore, it was possible to interview an informal support. Pertinent here is the fact that data were obtained from the functionally disabled elderly on their living arrangements, on the nature and extent of their functional disabilities, and on the sources and extent of the help they received. When the functionally disabled elderly reported receiving help from informal supports, one person usually was designated as the major source of help. Since we interviewed the person designated as the key informal support, we interviewed those who accounted for most but not all of the informal help received by the primary research subjects. Data were collected from informal supports on both caregiving effort and burden. For a set of nine Activities of Daily Living (ADL) and Instrumental Activity of Daily Living (IADL) tasks, informal supports were asked whether the primary research subject needed help, whether needed help was provided, and how frequently they, themselves, helped. Burden is conceived here as a construct separate from caregiving effort. Burden was defined as the impact of caregiving on the life circumstances of informal supports. An attempt was made to operationalize burden through relatively tangible aspects of respondent experiences. The premise was that the experiential indicators of burden would be more meaningful to policy members than a more abstract, less readily measurable psychological construct such as stress. Three aspects of burden were measured: employment, finances, and restrictions on personal domestic life. Informal supports were asked whether their caregiving prevented them from working. Those who worked were asked about potential restrictions such as a need to be able to leave work in case of emergency, a need to work close to home, and a need to be available to handle problems over the telephone. In the financial area, respondents were asked about a variety of goods and services they might have had to forego because of their long-term care expenditures. Concerning domestic life, informal supports who shared a residence with the primary research subject were asked whether their roles in long-term care affected their privacy, their free time, and their activities outside the household. It should be noted that the approach to burden measurement incorporated a built-in limitation. Informal supports were asked to make an inference about the impact of caregiving on their lives. Legitimate questions can be raised about the ability and willingness of informal supports to make valid reports of caregiving effects on their own life circumstances.

FINDINGS

PATTERNS OF HELP

Of patients interviewed at the four month stage, 82 percent had received some help (see Table 1). Forty percent had received help only from informal supports; 23 percent received help from both informal supports and organized services; and 18 percent received help only from organized services. According to reports of the functionally disabled elderly, the level of help from informal supports varied directly with level of functional disability. The more serious the functional disability reported, the more frequent was the help provided by informal supports. Receipt of organized services was positively associated with Medicaid status but was not associated with size of household. In other words, those living alone were not more likely than others to receive organized services.

TABLE 1

SOURCES OF HELP
(Percent Distribution)

Received no help	18.5
Help provided by organized services only	18.0
Help provided by informal supports only	46.3
Help provided by both organized services and informal supports	23.2
TOTAL PERCENT	100.0
TOTAL NUMBER	633

CHARACTERISTICS OF INFORMAL SUPPORTS

The informal supports interviewed were predominantly women (73 percent). Slightly over a quarter were spouses; another 30 percent were daughters. Only nine percent were sons. Most lived in close proximity to the primary research subject. In 59 percent of the cases, they shared a residence; in 21 percent of the cases they lived elsewhere in the same building.

Informal supports reported modest incomes. Two-thirds had incomes below $12,000; 86 percent had incomes below $20,000. The implication, of course, is that informal supports lacked financial resources with which they could be expected to pay for extensive services.

When informal supports were relatives, they were asked whether they had made any cash expenditures associated with care of the functionally disabled person in the three months prior to the interviews. Thirty-six percent reported an expenditure. For them the mean expenditure was $1,300 and the median was $175. The distribution of expenditures, therefore, is highly skewed. In a few instances, informal supports made substantial cash payments to help with long-term care. In the majority of cases, however, they spent little if anything. The modest level of expenditures is not surprising in light of the incomes reported by informal supports.

INFORMAL HELP

Informal supports perceived the primary subjects as needing extensive help (Table 2). Among the ADL and IADL tasks covered,

TABLE 2

INFORMAL SUPPORT'S PERCEPTION OF HELP NEEDED
(Percent Distribution)

TASK	PERCEPTION OF HELP NEEDED HELP NOT NEEDED	 HELP NEEDED	 TOTAL PERCENT	N[a]
Transfer	71.4	28.6	100.0	420
Dressing	66.5	33.5	100.0	418
Bathing	57.9	42.1	100.0	416
Medication	67.1	32.9	100.0	420
Going Outside	37.9	62.1	100.0	420
Traveling Short Distances	24.0	76.0	100.0	420
Personal Matters	27.1	72.9	100.0	417
Household Maintenance	27.4	72.6	100.0	347
Other Tasks	80.9	19.1	100.0	345

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[a] N does not always total 422 because of missing data or a screening question.

the category in which least assistance was seen to be needed was transfer, that is, help in getting into and out of bed and chairs. Even in this category 29 percent were seen to be needing help. Three-quarters were reported to be in need of help in travelling short distances. Less than half were seen to be in need of help with ADL tasks; a majority were reported as needing assistance with each of the IADL tasks except for the taking of medication.

Where help was seen to be needed, informal supports reported providing help in most of the task areas (Table 3). They claimed to respond to need to some extent in over 70 percent of the cases in the following task areas: help with personal matters, transfer, dressing, and medication. The domain in which they responded when needed least often (39 percent) was travelling short distances. The intensity of the help provided by informal supports, however, was relatively low. In three of the eight task domains help was provided less often than once a day. In three other domains help was provided on the average of once a day. In only two areas, transfer and mobility, was help characteristically reported as being provided twice a day.

TABLE 3

THE PROVISION AND INTENSITY OF ASSISTANCE BY INFORMAL SUPPORTS

TASK	PROVISION OF HELP		MEAN INTENSITY OF HELP[a]
	HELP PROVIDED	HELP NOT PROVIDED	
Bed and Chair	77.3%	22.7%	2.66
Dressing	74.1	25.9	2.18
Bathing	55.2	44.8	1.82
Medication	73.0	27.0	2.72
Going Outside	39.3	60.7	1.04
Traveling Short Distances	51.7	48.3	1.05
Personal Matters	77.7	22.3	1.04
Household Maintenance	58.5	41.5	1.60
Other Tasks	66.7	33.3	1.79

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[a] 1=less often than once a day; 2=once a day; 3=couple of times a day; 4=several times a day.

Surprisingly, the functionally disabled elderly and informal supports tended to disagree on the frequency of help provided by informal supports. Their reports were negatively correlated (r=-.23, p .01). By the account of informal supports, their frequency-of-help was also negatively associated with severity of functional disability as reported by primary research subjects (r=-.18, p .001). These findings can at least partially be attributable to the fact that severity of disability is linked to the presence of other services and involvement of other relatives (Table 4). The role played by the primary informal support is less at higher levels of disability as the configuration of helpers is larger. In other words, at higher levels of disability there is more extensive division of labor among helpers.

It is also of note that Medicaid eligibility has a positive effect on the presence of organized services beyond the effect of IADL disability (Table 5). In other words, at a constant level of disability, the Medicaid eligible are more likely than others to receive services. In Table 6 the link between participation of informal supports and participation of organized services is shown. The presence of relatives is negatively associated with the presence of services after disability and Medicaid status have been taken into account. In other words, reduced availability of relatives is associated with increased presence of services.

Both place of residence and relationship of the informal sup-

TABLE 4

MEAN DISABILITY SCORE[1] BY PRESENCE OR ABSENCE OF HELPERS OTHER THAN PRIMARY INFORMAL SUPPORT

OTHERS WHO HELP	MEAN DISABILITY	N	SIGNIFICANT[2] RELATIONSHIP
No others present	3.03	186	a b
Formal services present	3.94	110	a c
Relatives present	3.16	66	c d
Both present	3.90	55	b d

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[1] Disability combines ADL and IADL.

[2] Matching letters indicate signifcantly different means (p=.05)

TABLE 5

REGRESSION OF THE PRESENCE OR ABSENCE OF SERVICE HELP ON DISABILITY AND MEDICAID ELIGIBILITY

VARIABLE	b	STANDARD ERROR	SIGNIF-ICANCE
ADL	.005	.04	.90
IADL	.40	.04	.0001
Medicaid Eligible[1]	.19	.03	.0001
Relative Help[2]	-.30	.04	.0001
Intercept	-.31	.06	.0001
ADJ R^2	.31		
N	632		

[1] 1=Eligible, 0=Not Eligible
[2] 1=Help, 0=No Help

TABLE 6

REGRESSION OF THE PRESENCE OR ABSENCE OF RELATIVE HELP ON DISABILITY AND MEDICAID ELIGIBILITY

VARIABLE	b	STANDARD ERROR	SIGNIFICANCE
ADL	-.13	.04	.001
IADL	.49	.04	.0001
Medicaid Eligible[1]	-.06	.04	.08
Service Help[2]	-.31	.04	.0001
Intercept	-.02	.06	.76
ADJ R^2	.24		
N	632		

[1] Medicaid Eligible 1=Yes, 0=No
[2] Service Help 1=Yes, 0=No

TABLE 7

MEAN FREQUENCY OF HELP BY PLACE OF RESIDENCE

PLACE OF RESIDENCE	MEAN FREQUENCY OF HELP	N
In the same apartment as the primary research subject	-.04	211
In the same building, but a different apartment	.08	29
On the same block	-.19	12
Same neighborhood but not the same block	-.002	22
A distance away	.14	52

port to the functionally disabled older person affect the level of informal help provided. A summary frequency-of-help score was obtained by combining the responses in individual task domains and standardizing the resulting score. The final distribution of these frequency-of-help scores is negatively skewed with 65 percent of the informal supports falling more than one standard deviation below the mean. The data, therefore, indicate that highly intensive help was being provided only by a minority of informal supports. Surprisingly those who lived in the same apartment as the functionally disabled older person reported providing somewhat less frequent help than those who live some distance away or elsewhere in the same building (Table 7). The pattern, however, is not statistically significant. Failure to find more frequent help provided by those sharing a residence with the disabled older person is perhaps explained by the level of involvement of these persons in activities generally needed to sustain the household, such as; shopping, meal preparation, cleaning, and paying bills. In other words, they carried household responsibilities apart from specific long-term care tasks. The measure of informal care giving was not sensitive enough to reflect the degree to which their basic household duties may have increased because of the disability in the primary research subject. In the relatively rare instances in which sons are the primary informal supports, they tend to be intensively involved (Table 8). Although daughters are <u>frequently</u> involved as key informal supports, the intensity of their caregiving tends to be below average. When relationship to the older person is examined for those who share

TABLE 8

MEAN FREQUENCY OF HELP BY RELATION TO PRIMARY RESEARCH SUBJECT

RELATIONSHIP	MEAN FREQUENCY OF HELP	N
Spouse	.10	92
Sibling	.24	18
Son	.15	28
Daughter	-.19	103
Son-in-law	-.22	2
Daughter-in-law	-.17	9
Other Relative	.22	34
Friend	.02	33
Other	-.66	3

the same apartment, the relatively low frequency of effort on the part of daughters persists (Table 9) although the differences among the means are not statistically significant (f=1.60, p=.13). The relatively low intensity of effort on the part of these daughters may be explained by their employment patterns--i.e., 45 percent of the daughters who lived in the household were employed.

EFFORT AND BURDEN

It was hypothesized that frequency of help would be positively associated with burden, that at higher levels of effort on the part of informal supports there would be greater evidence of negative consequences for their life circumstances.

Because of differences in the kinds of burden questions asked of those who lived with the functionally disabled person and those who lived elsewhere, it was necessary to consider the two groups separately in examining the relationship between effort and burden. Among informal supports who share a residence with the elderly disabled person, there is a positive relationship between frequency-of-help and burden (r=.20, p=.003). When informal supports live elsewhere, however, there is no linear correlation between intensity of help and burden (r=-.01). Among those who share a residence with the functionally disabled older person, there is evidence that the relationship between frequency of assistance and burden is affected by the informal support's relationship to the

TABLE 9

MEAN FREQUENCY OF HELP BY INFORMAL SUPPORT'S RELATIONSHIP TO PRIMARY RESEARCH SUBJECT FOR THOSE WHO LIVE IN THE SAME APARTMENT

RELATIONSHIP TO SUBJECT	MEAN FREQUENCY OF HELP	N
Spouse	.09	91
Sibling	.24	13
Son	.06	14
Daughter	-.42	58
Son-in-law	-.22	1
Daughter-in-law	-.17	5
Other Relative	.50	15
Friend	-.06	12
Other	-.55	1

primary research subject (Table 10). In the case of spouses and daughters, there is a strong positive association between frequency of effort and burden (r=.36 and r=.46 respectively). When the informal support is a friend, however, the relationship is <u>negative</u> (r=-.57, p .05). Although statistically significant, this finding should be interpreted with some caution, however, since it is based on only twelve cases. When frequency-of-help was examined for its relationship to burden subscales, the same general relationship persisted. In the case of daughters, there is a statistically significant relationship between frequency-of-help and life style restrictions (r=.31, p .02).

For informal supports living outside the household, the implications of relationship to the disabled person for burden were also examined (Table 11). Although differences are not statistically significant, the pattern is of interest. In the case of daughters, there is a suggestion of a slight positive association between effort and burden; in the case of friends, the direction is again clearly negative.

TABLE 10

INTERCORRELATIONS BETWEEN CAREGIVERS FREQUENCY OF ASSISTANCE AND BURDEN FOR CAREGIVERS WHO LIVE IN THE SAME APARTMENT AS THE ELDERLY RESPONDENT

RELATIONSHIP TO THE ELDERLY RESPONDENT	CORRELATION BETWEEN BURDEN AND ASSISTANCE	N
Spouse	.36***	91
Sibling	-.14	13
Son	.41	14
Daughter	.46***	58
Daughter-in-law	.35	5
Other Relative	-.17	15
Friend	-.57*	12

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* P .05
*** P .001

TABLE 11

INTERRELATIONS BETWEEN INFORMAL SUPPORT'S FREQUENCY OF ASSISTANCE AND BURDEN FOR INFORMAL SUPPORTS LIVING APART FROM PRIMARY RESEARCH SUBJECTS

RELATIONSHIP TO THE PRIMARY RESEARCH SUBJECT	CORRELATION BETWEEN BURDEN AND ASSISTANCE	N
Spouse	--	--
Sibling	.34	5
Son	-.19	14
Daughter	.05	45
Daughter-in-law	-.05	4
Other Relative	-.08	19
Friend	-.34	21

Overall the data suggest that the link between effort and burden is mediated by the nature of the relationship. Where there is a greater obligation to participate in care because of a close family relationship and a shared residence, there is evidence that frequency of effort leads to burden for informal supports. In instances in which the help is more clearly voluntary as it is when provided by friends, effort, if anything, is negatively associated with burden.

DISCUSSION

The data are broadly supportive of the fundamental policy argument that participation in long-term care in home settings can have negative consequences for informal supports. Accordingly, an important immediate contribution of organized services in long-term care can be to reduce burden experienced by informal caregivers. The data indicate that at higher levels of disability, Medicaid eligibility increases the likelihood of presence of organized services. The introduction of organized services permits a reduction in frequency-of-help on the part of the primary informal support. When the involvement of the primary informal support is more clearly obligatory, lower levels of effort are associated with lower levels of burden.

At the same time, the research suggests that caution is advisable in using either burden or frequency of help reported by informal supports as a basis of establishing eligibility for publicly-financed services. Frequency-of-help accounted for only a small percentage of variance in burden. More importantly, however, the relationships among level of disability, presence of organized services, involvement of other informal supports, and frequency-of-help on the part of the primary informal support proved to be much more complicated than anticipated. The introduction of organized services appears to affect burden in the primary informal support only indirectly and in particular circumstances. The principle of taking a standard of burden for informal caregivers into account in setting home care service authorizations is attractive, but a good deal more should be known before such standards are used in setting service authorizations in individual cases. Further research is needed to obtain more adequate measures of informal caregiver effort and burden and to understand the effects of services on informal caregiver effort and burden.

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