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ABSTRACT

Although caregiving has become a major gerontological focus, less attention has been paid to differences in family responses to the elder's impairment depending on whether the disability is physical or mental and to the effects on family members beyond the primary caregiver. Data for this study were taken from in-person interviews with a subsample from a longitudinal survey of three-generalizational families. Respondents (N=63) included 18 relatives of elders with a physical illness or chronic disability, 19 relatives of elders suffering from a mental dysfunction, and 25 relatives who reported no illnesses and no caregiving. Interviewees were asked to describe their family situation and were evaluated for depression, degree of burden, and activities of daily living scale to indicate degree of impairment of relative. There were no significant differences between physically and mentally impaired groups on degree of impairment, burden, or depression. The activities of daily living items predicted burden in the physical impairment group. Moreover, in the physical group, families who provided greater frequency of care reported more burden, while in the mental group, families who provided less care reported more burden. (Author/ABL)

MENTALLY OR PHYSICALLY IMPAIRED ELDERS; FAMILY CONSEQUENCES

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With the increasing life expectancy and morbidity of the elder population, the effect on families of impairment in an older family member has become a major concern in the health and aging fields. Concern has especially been centered on the caregivers themselves, usually the spouse or adult daughter of the impaired elder, and the effects of caregiving responsibilities on the psychological well-being of these individuals. In many cases, the impairment requiring caregiving is Alzheimer's Disease. Less attention has been focused on the effects of an elder's health-related dependency on other family members besides the immediate caregiver, and on the type of health condition that necessitates care.

Thus, two questions organized this study: First, what are the effects on family members beyond the primary caregiver, if there is a primary caregiver, when older family members develop health problems? Second, what differences are there between families' responses to physical and cognitive decline?

The organizing concept is borrowed from the idea of "life

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event webs" as described by Pruchno, Blow, and Smyer (1984). We have adopted the term "ripple effects" to describe the effects on others in the life event web beyond the primary caregiver (See Figure 1).

Methods

Respondents

The respondents were all from the USC Study of Three Generational Families. In all, 1331 individuals responded to surveys in both 1972 and 1985. The oldest generation (G1) had a mean age in 1985 of 78; the G2s, 57; the G3s, 33. In 1985 and 1986 we conducted in-person interviews with 100 of these survey respondents, representing three types of families: (1) the older person had a serious physical illness or chronic disability, (2) the older person suffered from memory or cognitive impairment, and (3) the older person had neither. Families were identified by screening the surveys for respondents who identified themselves as caregivers or who referred to a memory disorder in an elderly parent or grandparent. Attempts were made to interview at least one member of each generation, including the elderly individual who might or might not be receiving care. G1 and G2 spouses were interviewed where available. All families that were interviewed lived within 75 miles of USC.

It is important to notice that this sampling differs from studies that advertise in some fashion for caregivers, and therefore, in which respondents are self-selected. Thus, the present study may be more representative of the families who are coping with the aging and decline of an elder. Nonetheless, we could identify a "primary caregiver" in most, but not all, families. For instance, sometimes two people were heavily involved, and each said that the other was primary. One striking observation was that caregiving was often taken on as a family chore, e.g., a married couple might both be helping the parent of one of them.

Two types of data were used: interview and paper-and-pencil. For analyses of the latter, we included no more than one member of each generation, choosing from each couple the one who indicated greater caregiving responsibility. The number of subjects for the paper-and-pencil analyses was 63: 18 whose older relative was predominantly physically impaired, 19 whose older relative was predominantly cognitively impaired, and a comparison group of 25. Mean ages of the three generations corresponded to the means of the entire survey sample. The 63 respondents included 70% women and 30% men, with the imbalance of women to men somewhat greater for cognitively than for physically impaired elders.

Measures

Interview. The construction and content of the interview have been described before (Hurwicz, 1986), and therefore will only be described briefly. Because respondents had already completed an extensive structured survey, the interview was semi-structured, allowing for more flexibility in responses. Much of the interview concentrates on declines in the health of the older family member, and the effects on the interviewee as well as effects on the rest of the family from the interviewee's point of view.

The interview of the impaired G1 also included a brief mental status test, to provide some index of the severity of any cognitive impairment.

Paper and pencil measures. Two instruments were administered to respondents at the time of the interview: a burden scale and a measure of depression. Indices such as the Burden Scale (Zarit, Reever, & Bach-Peterson, 1980) have been developed to assess the amount of burden and stress that are involved with provision of care. Other investigators such as George and Gwyther (1986) have argued for using ordinary sorts of indices of psychiatric distress, such as the CES-D (Center for Epidemiological Studies Depression Scale; Radloff, 1977). In the present study, both of these measures were employed, with the CES-D administered to all 100 respondents and the Burden Scale only to family members of elders with a health-related dependency.

For purposes of further description, families of elders with a health-related dependency were also asked to complete a brief ADL scale about the impaired elder and to indicate their frequency of contact.

Results

Interview

In order to describe ripple effects of caregiving on the families in this study, we have developed 10 categories for coding interview responses. At this time, one-quarter of the interviews have been coded.

Preliminary examination of these results suggest that the most frequent consequence of the health-related dependency on the family is some sort of _altered family relationship_, between the primary caregiver and some other person in the family. These altered relationships may be negative (e.g., greater tension between family members) or positive (e.g., "we've gotten closer"). Competing demands usually illustrate negative changes in family relations, e.g., having to choose between spending time with one's parent versus time with one's spouse, responsibilies toward one's parent versus toward one's own children. An example of an altered family relationship which results in greater closeness is the grandchild's providing support, either directly to the frail grandparent, or to their own parent who is caregiving.

The following are examples of altered family relationships, taken from the interview protocols:

> My husband may feel the tension because he's doing and I'm working and my parents are in need...I try not to have him do too much because I don't want him to get too much of it.

> When my father was very, very sick, [my sons] were with us; they were able to help, they were there to support.

The second most frequent consequence was readjustments in one's social life, for example, a daughter's not being able to attend civic meetings due to having to help her mother, or a grandson's not dating because he was living with his very frail grandfather, or a couple's changing their post-retirement plans. The following offers an example of this category:

> Activities have been stopped or postponed or else finally achieved with a lot of difficulty...anything that requires being away for more than a few hours...we just postponed [a trip] that I'm very upset about...

In third place was a category we call altered perspective on the part of younger generations. One illustrative quote is from a

50-year old woman whose parents each have a major list of incapacitating ailments:

> I've got a few years behind me now, and the birth of my grandchildren and my parents being in need, I can see the whole broad view of a person being born and dying.

A 55-year old woman described being frightened to see what it was like to live like this. And G3s make observations about "what all this is doing to my mother" and wonder what it will be like for themselves in the future.

We did not as yet find markedly different distributions of types of ripple effects for the two types of impairments. We think, however, that we have found one difference between these groups, which is described below.

Paper-and-pencil Measures

Table 1 summarizes the means and standard deviations for the paper and pencil measures.

Because of the fairly small sample sizes, it was not possible simultaneously to control for all variables that might possibly modify the results, such as gender of the family member, whether the family member lived with the elder, and whether the elder was institutionalized. Consequently, we repeated the analyses several times, by gender, or eliminating from the analysis respondents who lived with the impaired G1. We will present one set of findings, and simply note that the pattern of differences between relatives of physically and cognitively impaired elders could not be explained by variations in the nature of arrangements.

Because of unequal Ns for the three groups and unequal variances for dependent measures, a regression model was used to test for differences among groups. On depression, status (physical versus mental versus comparison) did not significantly predict CES-D. Relatives with a G1 in a nursing home did appear to be more depressed than the sample mean, but the N is too small to test the idea or to draw any conclusion.

On the Burden scale, the sample whose relatives were cognitively-impaired was somewhat more burdened than the physically-impaired sample. A problem in drawing inferences from this finding is that a number of G1s were both physically and cognitively impaired. Often the physical problems had preceded the cognitive. We classified them as cognitive if the impairment was severe and seemed most salient to the respondent. If these G1s were reclassified as physical, the difference in burden disappeared. What perhaps is more interesting are the more complex predictions (reported below), which held up no matter which classification of the dually-impaired was used.

Similarly, on ADL the relatives of cognitively-impaired elders tended to report more problems. However, this difference disappeared when the dually-impaired were reclassified. Under either assignment, family members of cognitively-impaired tended to report the elder as having more trouble with preparing meals and doing household chores, while mobility (stairs, walking) was somewhat more of a problem for physically-impaired. Ability to perform personal hygiene activities was not different according to type of impairment.

The more complex analyses tested the prediction that for the physically-impaired group, extent of disability would predict burden; whereas for the cognitive group, it would not. We regressed the ADL items on Burden and then on CES-D for both physical and cognitive groups. ADL significantly predicted burden for the physically-impaired group, with ability to prepare meals the strongest predictor. ADL did not significantly predict burden for the cognitive group. In other words, for family members of elders with physical illnesses, greater impairment was related to greater burden. ADL items did not significantly predict CES-D for either the physically or cognitively impaired groups.

Finally, we evaluated the role of frequency of contact. We took Burden as the outcome and used three predictors: status (physical versus mental), frequency of contact, and the interaction of status and frequency. The regression was significant. A breakdown (see Figure 2) showed that within the physically-impaired group, the family members with more frequency of contact (who presumably provided more care) reported more burden. Within the cognitively-impaired group, family members with less contact (who presumably provided less care) reported greater burden. While the same pattern held when CES-D was the dependent variable, the results were not significant.

Discussion

These results show some of the ripple effects of an elder's health impairment on the family. Of special interest are the ways in which the experience triggers reevaluations by younger generations of other family relationships and of their own development.

We have also tentatively suggested how burden scores may reflect a particular way in which the experience of having an elderly family member with a physical or cognitive disability is somewhat different. Neither is in itself more or less burdensome or demoralizing. For health-related dependencies due to physical illness, greater impairment was associated with greater burden. In contrast, higher burden was found for family members of cognitively-impaired elders who had less contact with their relative. The interview data shed some light on possible interpretations of this finding.

With relatively mentally intact impaired elders, more demands for care seem to lead to more burden. But late in the process of cognitive decline, family may recognize the impossibility of maintaining an emotional relationship and may give it up. In some instances, they reconstrue the demands of the very cognitively impaired elder by saying that the person is "not themself", or they view the problemmatic behavior as "not their fault". Through such mechanisms, it appears that stress and burden may be reduced. The following quotes from two interviews illustrate this notion:

> It is a condition where he is not responsible for what he says and does anymore. I know, even my mother voiced it, if she had the slightest idea this man would ever have turned this way, she would never have married him.

> My mother...knows no one, has no understanding at all. Her body exists, her soul departed many years ago. I loved her very much, we were truly good friends. I miss her very much.

TABLE 1

Means and Standard Deviations for Outcome Variables

VARIABLE	GROUP	N	MEAN
CES-D (20 items; possible score range 0-60)	Physical	18	10.33
	Cognitive	19	11.21
	Comparison	25	10.20
Burden (22 items; possible score range 0-88)	Physical	17	19.71
	Cognitive	18	23.89
ADL (5 items; possible score range 5-20)	Physical	17	12.76
	Cognitive	19	15.63

VARIABLE	SCORE	Physical	Cognitive
Frequency of Care	1 = Daily	4	5
	2	1	5
	3 = Weekly	5	3
	4	1	1
	5 = Monthly	4	1
	6	2	3
	7 = Annual	1	1

Figure 1

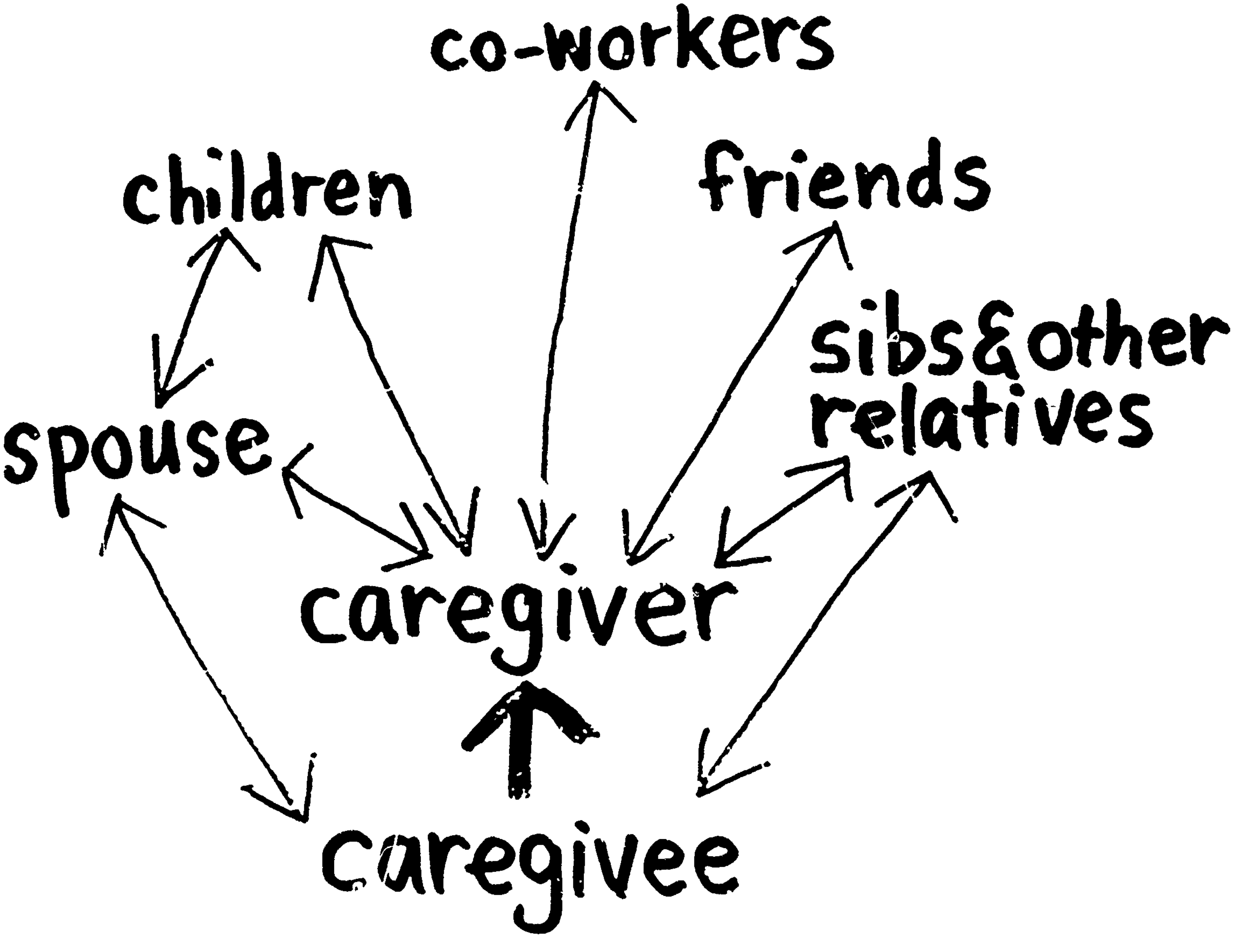
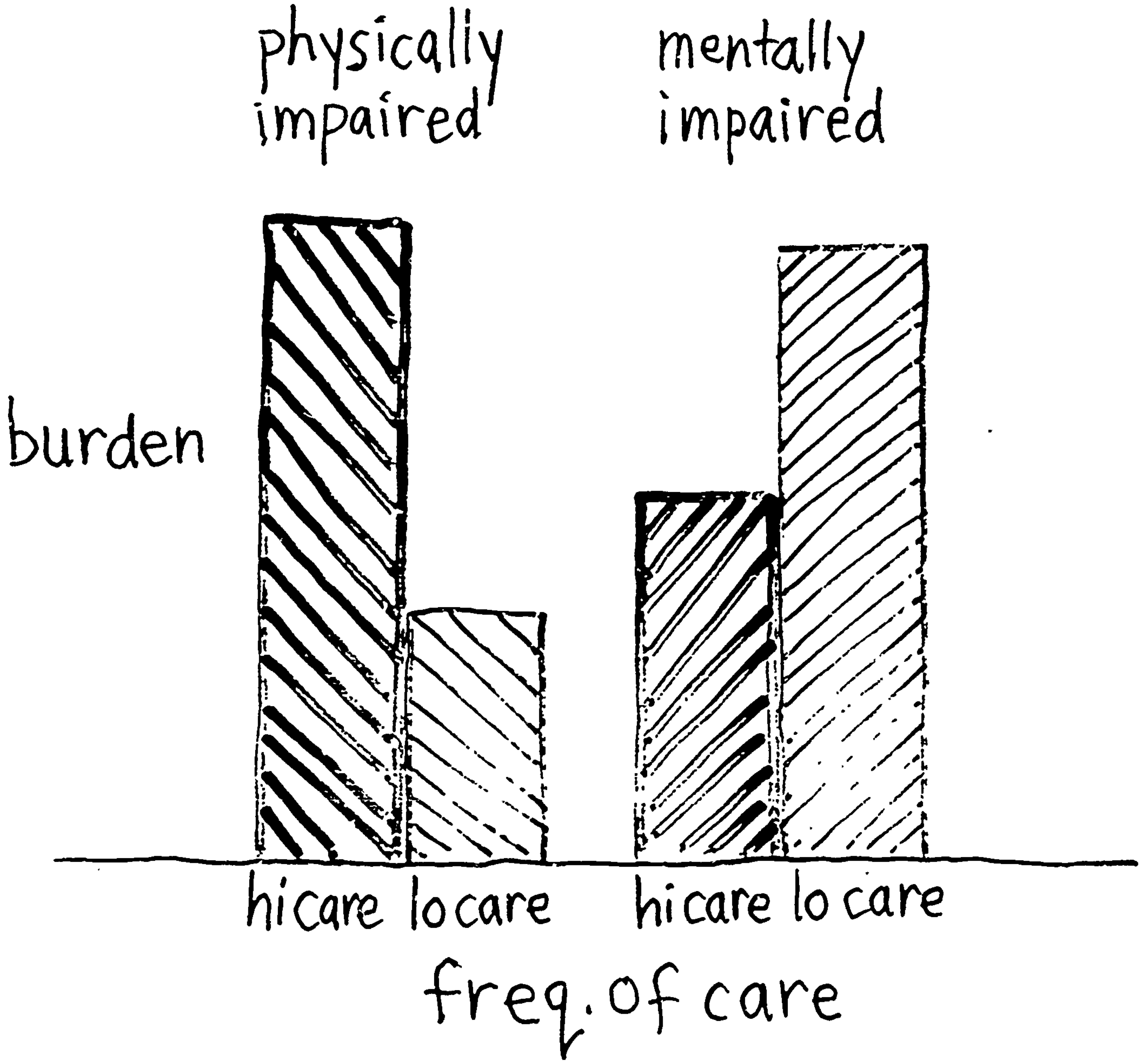

co-workers
children
friends
sibs&other relatives
spouse
caregiver
caregivee

Figure 2


physically impaired
mentally impaired
burden
hi care
lo care
hi care
lo care
freq. of care

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