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STRESS OF THE CAREGIVER: EFFECTIVE MANAGEMENT OF DEMENTIA PATIENTS IN HOSPITAL AND COMMUNITY SETTINGS

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This study explores the management problems among elders with dementia and their medical and family caregivers. Twenty-five patients were interviewed as well as professional health care personnel and a family member. Findings indicated that professional assessment facilitates home caregiving but has little bearing on successful coping by the caregiver. Variability of coping relates to the strategy employed.

Currently, dementing illness affects 2-4 million people; this number is expected to increase by 50 percent during the next 25 years unless major advances are made in the prevention and treatment of these illnesses.¹ What components comprise the treatment of these types of illness is uncertain, but most sources agree that the behavior of the affected individuals is determined by three factors: neuronal pathology, somatic health, and the quality of the personal and social support system.²

The primary form of irreversible demetia in middle aged and older persons is Alzheimer's Disease, which is characterized by a deterioration of the patient's capacity for self-care and of the ability to cope with the physical and social environment. There are, however, large individual differences in the rate of change and course of illness ranging from an abrupt decline and plateau to relatively stable behavior with only small decline before rapid deterioration.

The majority of older persons with dementia live in the community and not in institutions,³ with a family member being the most common care provider.⁴ The strain this poses for the family can be immense. In a recent study, families identified a wide variety of problems in care provision ranging from toileting to meeting psychological needs.⁵ The variation is due to numerous issues, including biological factors involving the extent of brain degeneration as well as constitution and heredity, and psychological factors like compensation and environmental stress which should be viewed socially, psychologically and medically.⁶

This paper addresses primarily the caregiver and the ways in which each handles the stress of particular situations. Morycz notes that problems presented by older individuals in various stages of dementia are frequently allowed to assume crisis proportions because caregivers either do not understand or deny the condition and because there are few community resources available to provide the necessary help.⁷ Clearly there are problems in the patient-caregiver relationship that contribute to the problems the caregiver faces. Two studies have reported physical violence, memory disturbances, catastrophic reactions, and sleep disturbances reported in elderly dementia cases.⁸ Caregivers also report problems for themselves citing depression, anxiety, family conflict, loss of friends, guilt, and difficulties assuming new roles and responsibilities.⁹ It is clear that the family's reaction is not usually attributable to a single factor.¹⁰

With the numerous problems facing the family, one recognizes no single pattern of caregiver behavior; families cope differently. Some initially deny the relative's cognitive impairment while others "doctor-shop" looking for a diagnosis that will disclaim the dementia.¹¹ Other families place unrealistic expectations on their ability to provide care, and one report suggested that families will often insist on providing home care even when professional advice is to the contrary.¹² Many families can even tolerate low-performing individuals for long periods of the time.¹³ In fact, for some careproviders, care for the patient often gives purpose to an

otherwise meaningless existence.¹⁴ Obviously, however, tolerance may vary among families.

But even with the variety of familial responses to the caregiving process, the financial, physical and psychological resources of the caregiver become strained as home care continues and deterioration progresses. Dementia, especially that of the Alzheimer's type, involves the family in a manner most other illnesses do not. The long extended nature of the disease process, the cognitive changes that ultimately annihilate the elder's capacity for self-help and which may result in the elder's objecting to being helped, as well as the personality transformation of the older person into someone the family no longer recognizes, place unparalleled psychological, social, and physical demands on the caregivers.¹⁵ It is this situation of living with a long continued neurological disorder that is the most difficult for the family to bear.¹⁶ Disrupted social and psychological ties and uncertain expectations make caretakers vulnerable to stress and the accompanying psychological and physical problems which follow.¹⁷ In one study Macmillan observed that when increasing strain on the families went beyond a certain level, irreversible rejection of the elder occurred and no further help was provided by the family to the elder.¹⁸ The variability in behaviors of dementing persons has made it problematic for careproviders in the community to provide the appropriate environment for care. In an attempt to understand the varying behavior patterns of dementia patients and identify intervention strategies that might improve effectiveness in caring for this population in the community, a sample of hospitalized dementia patients and their familial and hospital caregivers was studied.

This exploratory study of management problems among elders with dementia and their medical and family caregivers was conducted with the cooperation of University Hospitals of Cleveland, Ohio, and the Judson Park Retirement Community in Cleveland. Twenty-five elders diagnosed with a dementing illness were interviewed. Sixteen of the 25 were hospitalized in the Neurology Unit of University Hospitals, while nine resided in the health unit of the retirement com-

munity. The patient and a family member were interviewed by a research assistant. This was a sample of all dementing elderly patients receiving care during a five-month period in these two settings. A semi-structured interview schedule was used to collect most of the data. Also, some data were retrieved from medical records.

Dementing persons are not a homogeneous group from either an etiological or a behavioral perspective. Patients with identical diagnoses will differ in their behavioral patterns because they may be in various stages of the disease process; they may have as well preexisting personality and cognitive differences. Some combinations of behavior exhibited by patients are more likely to be difficult for caregivers than are others. The following questions were asked:

1. What are the behavior patterns of dementing elders?
2. What behaviors are the most problematic?
3. What management strategies are the most effective for family and staff?
4. What is the experience of the caregivers of dementing elders in the caregiving situation?

Data were collected on the following variables:

1. *Patient characteristics*, which included age, sex, race, source of payment, and involvement of relatives and/or significant others. Psychotropic medications, when utilized, were also recorded.

2. *Patient diagnosis*, which refers to the medical and psychiatric diagnoses contained in the medical records at the time of the study, especially the type of dementia, if known.

3. *Patient functioning*: Both physical and mental impairments of sample patients were assessed, utilizing two short, widely used screening devices, the Mini Mental Status Exam and the Katz Index of ADL, (Activities of Daily Living).¹⁹

4. *Patient behaviors*, which included a wide range of deviant and/or dysfunctional behaviors associated with dementia, many of which are regularly observed by professional caregivers. Measures of these behaviors were made for each patient in the study by nursing personnel, utilizing a revised version of the Ward Behavior Inventory.²⁰ This instrument

lists 240 potential behaviors on which degree of maladaptation is rated for each patient. Each was rated as to occurrence and frequency of behaviors itemized in the Inventory. In addition, primary caregivers were asked to identify what they regarded as the most problematic behaviors of their dementing relatives. In follow-up interviews by telephone one month after discharge, the caregivers of Neurology Unit patients were asked to reassess these behaviors in light of professional interventions. Management of patients recommended at the time of discharge was identified, and caregivers were asked if these recommendations were being used, and, if so, whether the management was effective.

5. *Careprovider's management problems* were assessed by asking hospital and family careproviders what problems they had and how they dealt with them.

6. *Impact of dementia on family caregiver*: caregivers were asked what feelings they had regarding the care of their demented relative.

FINDINGS

Description of Subjects:

Sixteen women and nine men participating in this study had a dementing illness. The mean age of participants was 78 years. Among them, 60 percent were widowed, 4 percent were divorced, and 36 percent were married. Sixteen subjects were Caucasian and nine were Black. A majority of the subjects had diagnoses of Alzheimer's Type Dementia (60%). Other diagnoses included MultiInfarct Dementia (16%), simple "Dementia" (8%), and organic brain syndrome (4%). Another 8 percent were demented as a consequence of Parkinson's Disease. Two were receiving tranquilizers, and another two received mood elevators. Nine were taking anti-psychotic drugs on a continuing basis, while four were taking psychoactive medications of various other kinds. The remaining eight were receiving no psychoactive drugs at all. Most subjects required at least some assistance in daily living as measured by the Katz' ADL Scale.

Management Issues.

In order to develop a better understanding of management issues of elderly demented patients, the interviewer asked family members what behaviors and combinations of such were noted, whether these included a decline in memory function, neglect of hygiene, increase in denial of symptoms, depression, belligerence, hearing or language impairment, withdrawal, and increased anxiety. Caregivers were asked to name what they perceived to be the three most problematic behaviors in order of magnitude prior to hospitalization or moving to the health care unit at Judson Park. A considerable variety resulted. (See Table 1.)

TABLE 1
RATINGS OF PROBLEMATIC BEHAVIORS
BY FAMILY MEMBERS

Problematic Behavior:	Most N	Second Most N	Third Most N
1 Bathing	1		3
2 Dressing		2	
3 Medication	1		1
4 Memory	2	3	6
5 Remaining in bed		1	
6 Eating	2	5	2
7 Housework	2	2	
8 Hostility	2	2	
9 Wandering	3	3	
10 Various others	11	6	13

Family caregivers felt that their success in managing the most problematic behavior was "high" (42%), "some" (20%), and "none" (38%). On the "second most problematic behavior," management success was "high" (33%), "some" (29%), and "none" (33%), while on the "third most prob-

lematic behavior" success was "high" (19%), "some" (52%), and "none (29%). (Percentages do not total 100 due to missing information.)

Staff on the Neurology Unit and in the health unit of Judson Park, also asked to identify problem behaviors of the patients with dementia using the Ward Behavior Inventory compiled by nursing personnel, indicated behaviors which were highly consistent with those identified by caregivers before hospitalization. "Usual" behaviors occurring in more than 50 percent of the sample included: needs help with dressing; needs help in washing; has to be helped in bathroom; shows no interest in magazines, radio, or television; doesn't move about unless directed into some activity; and must be directed to take part in activities. "Occasional" behaviors occurring in more than half of the subjects were: acts bewildered and confused; has to be reminded what to do; resists or refuses to follow directions; and ignores people or objects around him or her.

A series of relevant management procedures were already in place, both at University Hospitals and at Judson Park, and were applied in a more or less standard way to all patients. They may be summarized as forms of physical restraints, and as assistance with various essential activities such as eating and toileting. Measures such as catheterization were routine for incontinent persons. A number of behaviors, however, appeared not to be managed at all. Affective states, for example, which in themselves were not disruptive, tended to be either disregarded or dealt with in passing by a solicitous question or two. The more agitated states were quelled by medication.

Follow-up:

Following discharge from the Neurology Unit, the family members of the 16 patients were reinterviewed to determine if the discharge plan was helpful in subsequent care of the dementing elder and to determine management procedure effectiveness since discharge. Measurement of problematic behaviors and interventions at follow-up showed that 21 per cent of the states, for example, which in themselves were not

effective," 21 percent thought them "little" effective, and 54 percent felt that their procedures were highly effective. Since caregivers expressed limited feelings of effectiveness in managing the elders with dementia, caregiver coping is of obvious concern. All 16 caregivers felt that their elder's illness had had an effect on their own feelings; they noted increased helplessness, anger, sadness, worry or denial. Many felt that they needed more support from others, needed to pay more attention to the elder or felt an increased sense of obligation. Fifty percent of the sample experienced at least three or more of these effects.

Some efforts to work with families during the period of hospitalization was made by hospital staff. The results of these efforts appear to be that families were more likely to use community resources after hospitalization than before, and a number reported improvements in their abilities to manage problematic behaviors.

Dementia is, of course, apart from assessment and medication, not so much a medical as a management issue, and, in fact, most insurances make no provision for maintenance of the person with dementia, a point raised by a number of respondents. Family functioning, as has been suggested, may alter dramatically on account of dementia, however. Despite considerable variation in the reactions of families in this study, it is clear that the stresses generated by new demands for coping and adaptation were felt by everyone. Many expressed feelings of isolation, of being overburdened, of conflicts with other family members in questions of responsibility and management, and, in general, the need for support, both within the family itself and from elsewhere. It is, therefore, significant that the data indicate that only a minority of families sought any assistance in the community.

Discharge planning involved multiple considerations in most cases. Family time availability was the greatest single factor, particularly for patients who were returning to family living. Although there is a need for a more active approach to family counseling and education, some effects were clearly achieved in that social services were much more utilized in

the period following discharge than had been previously the rule. Receptivity to and cooperation with advice given at the time of hospitalization was high. Both findings suggest that patients and families are often receptive to the recommendations for hospital personnel, and, in addition, that such advice and education is, when given, effective.

While the results of this study indicate the advantages of professional assessment and education to facilitate home caregiving, it does not answer the larger issue concerning the variability in families' capacities to cope with a dementing illness. Many other studies—this one as well—readily identify problematic behaviors of the elders and their various effects on the caregiver. What we need to understand better is how people cope and what coping process is effective.

Interviews with caregivers in the hospital and at home provided a glimpse into the coping process. Pearlin and Schooler identified three types of coping: 1. Responses that modify the situation or eliminate the source of strain, 2. Responses that control the meaning of the experience before it becomes stressful, and 3. Managing the stress once it exists.²¹ While, the majority of caregivers use a combination of these types as the dementing illness progresses and behavior changes, the most popular type is coping with the stress once it exists. The caregivers could readily identify the problematic behaviors and repeatedly exercised an effort to deal with them. Repeating things endlessly for memory problems as well as continuous prompting to eat are examples of such coping behaviors. The caregivers also coped at times by eliminating the source of stress and deciding to institutionalize the elder.

That decision, though, is often a difficult and painful one to make. This type of coping also includes the caregiver who denies there is a problem or another who says that "I have learned to turn him off and sit on the porch." The second type of coping process, responding in a way to control the meaning of the event before it becomes stressful, may be the most successful approach to coping for the caregiver. Being able to say "Things could be worse" or "We're all in the

same boat" or to ignore selectively problem areas and magnify what is gratifying in the caregiving relationship are all ways to control the meaning of the experience after it occurs but before it emerges as stressful. One daughter said that she tells herself and her mother that "Her mother has a big strong daughter to depend on," thus minimizing problem areas and magnifying a strength in the caregiving relationship. Of course, the meaning can be altered in a more negative direction which impedes successful coping, such as the caregiving husband who was hostile toward his wife and described her as "Bossy and uncooperative," saying that she would improve "when she had a mind to."

Unfortunately, failure in coping by a family member is viewed as an individual's failure. Pearlin and Schooler warn that some coping functions only help endure what cannot be avoided and "coping failures, therefore, do not necessarily reflect the shortcomings of individuals; in a real sense they may represent the failure of social systems in which individuals are enmeshed."²²

In summary, all caregiving families cope with strain. While successful coping involves the processes used by the caregiver, it also involves the broader social system in which the caregiving is rendered. Professional institutional settings like the acute care hospital in this study should provide information on management techniques and available resources for the caregivers. But as important is the use of effective coping strategies by the caregiver. While three types of coping are used by caregivers, it is clear that flexibility is the key to success. The caregiver who only copes with the stress once it exists or only copes by eliminating the source of stress has placed obstacles in the way of caring for a dementing elder. At times these techniques may be helpful, but they need to be used in conjunction with altering the meaning of the event before it becomes stressful. It is only this last type of coping—altering the meaning—that touches the psychological dimensions of caregiving, thus helping the caregiver face the responsibility and loss involved in providing care to a dementing elder.

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