Are physicians meeting the needs of family caregivers of the frail elderly?

SHARI L. BROTMAN, MSW, PSW
MARK J. YAFFE, MD, CM, CCFP

OBJECTIVE To explore expressed needs, both formal and informal, of family caregivers of frail elderly. To evaluate roles of physicians.

DESIGN Questionnaire survey of members of the Montreal Jewish community providing care for frail elderly family members.

SETTING Jewish community of Montreal.

PARTICIPANTS Volunteer caregivers who were caring for a family member or friend 60 years or older, who had greatest responsibility for providing physical or emotional support to an elderly person, who saw themselves as caregivers, and who could speak English or French were studied. Of 118 volunteers, 32 were excluded because they withdrew for personal reasons or because they did not meet study criteria.

MAIN OUTCOME MEASURES Demographic variables, functional status of the care receiver, use of home care services, and needs assessment to identify additional services.

RESULTS An average of 75.4% respondents did not use formal support services. Just under half of caregivers were dissatisfied with the attention they received from the health care system, and more than one third expressed feelings of stress, depression, guilt, and isolation.

CONCLUSIONS Hypotheses for this discontent are presented. Physicians may be uninterested in helping caregivers; even if they were receptive to counseling caregivers, they could be poorly remunerated for the types of counseling sessions that are usual for caregivers; and being a professional caregiver to family caregivers is demanding in itself.

OBJECTIF Explorer les besoins, formels et informels, des membres de la famille qui apportent soin et soutien à la personne âgée à risque de perte d'autonomie. Évaluer les rôles du médecin.

CONCEPTION Enquête par questionnaire auprès des membres de la communauté juive de Montréal qui prennent soin de malades âgés dans leur famille.

CONTEXTE Communauté juive de Montréal.

PARTICIPANTS Les soignants d'un membre de la famille ou d'un ami de plus de 60 ans, qui sont principalement responsables d'assurer un soutien physique et émotionnel à une personne âgée, qui se considèrent eux-mêmes comme soignants et dont la langue est le français ou l'anglais. Parmi les 118 participants potentiels, 32 furent exclus, soit à leur demande pour des raisons personnelles, soit parce qu'ils ne répondaient pas aux critères de l'étude.

PRINCIPALES MESURES DES RÉSULTATS Variables démographiques, état fonctionnel du malade, utilisation des services de soins à domicile et évaluation des besoins pour identifier la nécessité de services supplémentaires.

RÉSULTATS Parmi les répondants, 75,4% n'ont pas fait appel aux services de soutien conventionnels. Un peu moins de 50% se sont dits insatisfaits de l'attention accordée par le système de santé, et plus du tiers ont exprimé des sentiments de stress, de dépression, de culpabilité et d'isolement.

CONCLUSIONS L'article présente les hypothèses expliquant ce mécontentement. Les médecins sont possiblement peu intéressés à aider les soignants. Même s'ils sont réceptifs à l'idée de donner des conseils, ils sont possiblement mal rémunérés pour le type de counselling familier aux soignants. Il est exigeant pour un professionnel des soins de venir en aide à la famille soignante.

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THE AGING PROCESS CAN PRODUCE many burdens for the elderly, while health represents a strong predictor of their psychological well-being.[1] For frail elderly in particular, caregivers have an important role in promoting mobility, social activity, appropriate use of medications, and interventions to prevent new problems or deterioration in existing conditions.[2]

We all are challenged to maintain or improve the quality of life, safety, and psychological and physical stability of these aging individuals. In this context, the immediate family represents the main source of reliable support for elderly

Ms Brotman, *a social worker at the McGill University School of Social Work Consortium for Ethnicity and Strategic Social Planning, was employed by Jewish Support Services for the Elderly of Montreal at the time of this research.* **Dr Yaffe**, *a Fellow of the College, is Associate Professor of Family Medicine at McGill University and is Chief of the Department of Family Medicine at St Mary's Hospital in Montreal.*

people who are no longer independent; usually wives or daughters provide this care.[3]

Despite rewarding and positive aspects of the caregiver role, family members are often poorly prepared for the physical, emotional, and psychological tasks required of them. Caregivers themselves suffer from pressures and responsibilities that can lead to their own emotional, psychological, and physical stresses.[4-8] Often old or unprepared, they sometimes tolerate poorly these strains of caregiving.[9] It has been suggested, for example, that caring for a close relative, especially a spouse who has become demented, is one of the most demanding situations encountered.[9-11] Consequently, caregivers are likely to have constricted social lives and reduced leisure time.[12] They report low morale[13]; physical and emotional exhaustion[14]; and excessive depression, anxiety,[15] and "strain"[7]; and they try to balance the "should" of caregiving (the desire to do all) with the "could" of caregiving (what they are actually able to do).[16]

Table 1. **Caregiver characteristics**

PREDOMINANT CHARACTERISTICS	PERCENTAGE
Canadian born	62.4
Married	82.6
Female	83.7
Educated	
• Completed high school	59.3
• Completed university degree	37
Older than 60 years	58.5
Related to care receiver	
• Spouse	54.3
• Adult child	38.7
Had provided care for 1 to 5 y	62
Had concurrent personal (limiting) illness	46.4
Had filial support (minimum of one child)	80.3

For most elderly and their families, illness onset or a crisis associated with it is the initial cause for formal entry into the health and social service network. While public health care and social services for the elderly have generally improved over the years, service use appears to be relatively low for caregivers and their families. According to Bergman,[17] this crisis or illness onset is often just the tip of the iceberg of the past years, as well as the expected future years, of caregiving.

To deal adequately with the physical and psychological needs of a patient, physician and family must often work in concert, as partners. A demonstration project on care of the elderly from Toronto's Baycrest Centre indicated that, if the needs of older people with families are to be met, planning, policy, practice, and delivery of services should focus on the capacities, needs, and problems of the entire family, rather than on those of the aged individual alone, in order to enhance and prolong care provided within that family.[18]

This reality requires the health care professional, as a first contact for caregivers, to identify presenting problems and to treat not only the older patients, but also their families. In this context, physicians must understand the complex feelings, experiences, and imperatives of caregivers. Emotional needs must be put into proper context if the health of caregivers, as well as the vital support provided for their elderly relatives, is to be maintained.[2]

The elderly in Canada currently make up 11.5% of the general population. By the year 2006 an estimated 15% of the population will be 65 or older; this group will be 25% of the whole by the year 2026.[19] The Montreal Jewish community, where the elderly make up 21% of the total Jewish population, currently illustrates this future situation in microcosm.[20] How this population is functioning was of particular interest. A study, therefore, was designed to explore expressed needs, both formal and informal, of family caregivers of frail elderly.

Caregivers, whether spouses or adult children, looking after loved ones at home or in institutions were surveyed on their experience, coping abilities, life satisfaction, and informal family and friend support systems. Use of formal services, experience with the health and social service sectors, and concerns and degree of satisfaction with this aspect of the public sector were also evaluated. This paper addresses these three latter issues and discusses implications for clinical practice and for further research.

METHOD

Volunteer caregiver participants were recruited through announcements sent to community organizations working with elderly or caregivers, social service agencies, chronic care institutions, hospitals, supported housing programs, day centres, local community service centres, clergy, and interested physicians. The criteria for caregiver inclusion into the study included:

1. The respondent provided care for a family member or friend 60 years of age or older;
2. The caregiver had the greatest responsibility for providing physical or emotional support to an elderly person;
3. The potential subject identified herself or himself as a caregiver; and
4. The participant could speak English or French.

As part of a larger pre-tested questionnaire examining a range of caregiver issues, data for this report were collected using the following:

- a list of demographic variables;
- a functional status subscale of the OARS Multidimensional Functional Assessment Questionnaire[21] to measure 1) physical abilities of the care receiver (ADLs): eating, dressing and undressing, grooming, walking, transfers, hygiene, and toilet use; and 2) cognitive abilities of the care receiver (IADLs): using the phone, using transport, shopping, preparing meals, doing housework, self-administering medication, and handling money;
- a closed-ended formal services scale developed by Baumgarten[9] to explore the use of the following services: homemaker, home nurse, physiotherapist, occupational therapist, social worker, day hospital or recreational programs, respite care, foster homes, and Meals on Wheels (from this scale frequencies of service use were calculated); and
- a needs assessment protocol to identify additional service needs (private communication from S. Duder) using a standardized series of open-ended questions in which subjects were prompted with general enquiries as to their need for, use of, satisfaction with, and barriers to receiving formal and informal health and social services. Frequencies of responses were calculated through the groupings of common responses.

The questionnaire was administered to caregivers (in the absence of care receivers) by trained English- or French-speaking interviewers in one or two sessions lasting 2 to 2 ½ hours. The data were analyzed using SPSS (Statistical Package for the Social Sciences).

RESULTS

One hundred eighteen caregivers volunteered to participate. Thirty-two individuals ultimately did not take part because they either did not meet study criteria or else felt burdened by personal issues, such as time commitment to their care receiver or the recent death of a family member. The remaining 86 respondents were predominantly Canadian born, married, educated women older than 60, slightly more likely to be a spouse than a mature child, and in a caregiver role 5 years or less (*Table 1*). Just under half of the caregivers had concurrent limiting illnesses of their own, but most of them had potential support from their own children, most of whom were 20 years of age and older and living in Montreal.

Table 2. **Use and accessibility of formal services**

REASONS FOR DISSATISFACTION	DISSATISFIED CAREGIVERS NO. (%)
Doctors not compassionate or supportive	14 (31.8)
Misdiagnosis	5 (11.4)
Services terminated	4 (9.1)
Wrong medication or overmedication	3 (6.8)
No discharge planning	2 (4.5)
Wrong placement	2 (4.5)
Insensitivity to language or culture	2 (4.5)
Concerns not addressed	1 (2.3)
Unidentified reasons	8 (18.2)
TOTAL	44 (100)

The caregivers were evidently looking after truly frail elderly because care receivers were mostly older than 80 (63%), and primarily suffering from neurological diseases of the elderly (72%), including Alzheimer's disease, Parkinson's disease, unspecified dementia, and strokes. Care receivers were limited in their ability to perform ADLs: eg, 67.4% required help with bathing and 52.3% needed help for ambulation.

Just over half of caregivers were living with the care recipient; 28.2% of care receivers were institutionalized and 21.2% were living independently. Seventy-three percent of caregivers could not leave the care receiver home alone for any length of time, and 54.6% did not have assistance with the ADLs with which they were most preoccupied in helping the care receiver: making telephone calls, getting to places out of walking distance, shopping, preparing meals, doing housework, taking medication, handling money, eating, dressing, making transfers, and caring for personal hygiene.

While most caregivers agreed there were positive and reaffirming aspects to the role, they also expressed feelings of stress (37.1%), depression (37.1%), guilt (37.1%), isolation (38.4%), and fear (10.5%).

The 11 formal community services potentially available to assist the caregivers interviewed (including Meals on Wheels, respite care, and day centre), were surprisingly underused; an average of 75.4% of respondents did not use these services (*Table 2*). Even if use of those services had been desired, an average of 33.8% of respondents would not have known how to access them.

It is noteworthy that 41.9% of caregivers reported dissatisfaction with the health care system. *Table 3* highlights the factors accounting for this unhappiness; the greatest discontent was with physicians (38.9%) who were reported to be unsupportive or incompassionate. Caregivers saw the physicians' overriding concern as the ill person, in this case the care receiver. Caregivers also believed that they were ignored by doctors, particularly at crisis times, including the period of initial diagnosis. They indicated they required support and information from medical professionals to be able to help the care receiver more effectively and to promote their own long-term health.

Lesser areas of concern included perceived disease misdiagnosis, inappropriate prescription of medication or overmedication, and termination of desired services. By contrast, only 19.8% of caregivers expressed dissatisfaction with the support from the social services system, the most common complaint being having to wait too long to receive assistance.

DISCUSSION

Using formal services helps to buffer the effects of stress on health.[5] Such services can help caregivers find the free personal time necessary to maintain or develop social contact with friends and family, to rest, to engage in recreational activities, and to facilitate movement through the complex health and social service network. Despite the positive benefits of such support systems, we observed low use of these resources by caregivers. This corroborates information published in other studies indicating that caregivers underuse available services.[9,22] Lack of information about appropriate resources is an important reason for not accessing the needed services.

Physicians have a vital role in helping caregivers. At a basic level there is the responsibility to help caregivers locate much needed resources. However, it should extend to giving instrumental advice; to examining dysfunctional relationships between caregiver and care receiver; to discussing incongruence between parental expectations and filial obligation; to supporting caregivers and telling them that their feelings of resentment, anger, frustration, ambivalence, and demoralization are normal; and to encouraging them to take care of themselves.[2] The caregivers surveyed did not, however, believe their needs were being addressed.

Several explanations for the poor perception of physicians are proposed. The first is that physicians are uninterested in their potential roles of assisting caregivers. Indeed, when physicians' offices are provided with comprehensive resource manuals, doctors' use of and interest in them is low.[23] As well, our own experience and that of some physician colleagues who organize CME programs on this topic has been one of low physician turnout.

Another interpretation is that, even if physicians were receptive to counseling caregivers, such interactions often occur in the context of a 10- to 20-minute office encounter or an acute telephone intervention, neither of which are, in the minds of some doctors, appropriately remunerated. In Quebec, for example, the medicare system pays for psychotherapy only in sometimes impractical 30-minute time aliquots, while telephone discussions go unpaid.

A third hypothesis is that the burden of being a professional caregiver to family caregivers is demanding in itself. In the context of a busy workday, a physician could have to counsel and support several caregivers, and there are few systems available to buffer a stressed physician. As well, physician comfort or discomfort in discussing caregiver issues is influenced by his or her own life cycle issues,[24] personal values, and sense of family responsibility, particularly if they revolve around caregiving activities. Consequently, doctors often choose a path of least resistance and avoid meaningful contacts with caregivers.

Table 3. **Causes of dissatisfaction with the health care system**

REASONS FOR DISSATISFACTION	DISSATISFIED CAREGIVERS NO. (%)
Doctors not compassionate or supportive	14 (38.9)
Misdiagnosis	5 (13.9)
Services terminated	4 (11.1)
Wrong medication or overmedication	3 (8.3)
No discharge planning	2 (5.5)
Wrong placement	2 (5.5)
Insensitivity to language or culture	2 (5.5)
Concerns not addressed	1 (2.8)
Unidentified reasons	3 (8.3)
TOTAL	36 (100)

Our findings on caregiver need, service underuse, and lack of ability to access services parallels closely caregiving data on dementia patients by

Caserta et al[25] and on frail and disabled adults by Snyder and Keefe.[26] In the former study low use, despite apparent need, was attributed in part to caregiver unreadiness to actually accept help.

Thus, another interpretation of our findings of caregiver discontent with physicians could be that doctors spend time with caregivers, but that it is occurring during periods of intense caregiver stress when they are unable to absorb everything being said to them. This hypothesis would, thus, show a need for an ongoing doctor-caregiver relationship. Nonetheless we have concerns that an initial negative encounter with physicians could make caregivers reluctant to again seek out medical professionals to help them locate needed resources.

Our data must be interpreted in the context of a relatively small sample of self-selected caregivers. Given the stated objectives of the study, it is possible that participating in the research was the vehicle for a group of dissatisfied caregivers to express their unhappiness. Our sample of caregivers had been in this role for a relatively short time, and therefore might not have had opportunity to adapt to the ups and downs of the situation. However, for most caregivers, the burden gets worse; hence, expectations of the system should increase, rather than decrease, with time.

Finally, our sample was predominantly limited to the experience of one ethnic group; therefore, one is tempted to limit generalization of results solely to that group. However, our experience working in multicultural settings suggests that the opinions of our respondents likely reflects that of the community at large.

CONCLUSION

The role of the health care and social system in maintaining the health of caregivers needs continued review; their needs could be overlooked. Physicians can help to bring the entire family together in family conferences, to include the extended family in caregiver roles, and to stimulate a comprehensive health plan for the frail elderly while keeping the long-term needs of the primary caregiver in mind.

Just as cardiopulmonary resuscitation courses and prenatal classes are taught to the public to deal with possible future problems, so should medical, social work, and other professional groups organize and encourage participation in caregiver courses before a crisis or acute situation arises. New means need to be developed to transmit up-to-date information on community resources to physicians concisely and accessibly. Computer data files could be one solution. As well, physician focus groups could ascertain how other forms of information and skills can be effectively and concisely transmitted to doctors.

The solutions proposed could ensure that services received by frail elderly and their families meet their true needs. Given the apparent positive effects of the use of formal services on the health of caregivers, the roles played by health care professionals must be clarified and expanded if caregivers are to be able to maintain good health over the long-term. ■

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Requests for reprints to: *Dr Mark J. Yaffe, Family Medicine Centre, St Mary's Hospital, 3830 Lacombe Ave, Montreal, QC H3T1M5; fax (514) 345-3760*

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