

# FAMILY CAREGIVERS OF THE FRAIL ELDERLY A Jewish Communal Response To Expressed Needs

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*This study explores expressed needs of family caregivers of the frail elderly of Montreal. Particular attention was paid to comparisons between Jewish caregivers of Ashkenazi and Sephardi origin. Younger caregivers were significantly more able to gain access to formal resources, as well as to maintain more informal family and friend support. In contrast, older caregivers felt more isolated and had lower life satisfaction. Sephardi caregivers were significantly more isolated and less able to mobilize outside resources than Ashkenazi caregivers. All caregivers expressed significant service needs in areas of financial support, assisted transportation, ongoing counseling, and respite care.*

The main source of care for the frail elderly comes from individual family members (Baumgarten, 1990; Baycrest Centre for Geriatric Care, 1985; Brody, 1981; Malonebeach & Zarit, 1991; Shanas & Maddox, 1976; Stoller, 1983), most of whom are wives and daughters still living near their elderly relatives (Departments of Community Health of the Montreal General Hospital and the Verdun General Hospital, 1991; Stone, et al., 1987). Their role as caregivers is both challenging and rewarding in many ways, but frequently exacts a heavy toll. Caregivers are often burdened with physical and psychological tasks that can lead to emotional, psychological, and physical stresses (Baillie et al., 1988; Cantor, 1983; Cohen & Eisdorfer, 1986; Gallagher, 1985; Gottlieb, 1987). They are often old and/or may not be well prepared to tolerate the physical and psychological strain of caregiving (Baumgarten, 1990). In fact, it has been suggested that caring for a

close relative, especially a spouse who has become demented, is one of the most stressful situations that can be encountered (Aronson & Lipkowitz, 1981; Baumgarten, 1990; Rabins, 1984). In addition, the caregiver is likely to suffer from a constriction of social life and a reduction in available leisure time (Ross & Kedward, 1977). As a result, caregivers of physically and/or emotionally frail elders report low morale (Fengler & Goodrich, 1979), physical and emotional exhaustion (Farkas 1980), excessive depression, anxiety (Grad & Sainsbury, 1968), and "strain" (Cantor, 1983).

For the care-receiver, however, the care given by family members represents an essential component of care. The family remains the most reliable source of support for its older members (Renaud et al., 1988; Sussman, 1976). Even for elderly who are institutionalized, frequent contact with the informal caregiver remains essential to satisfaction and quality of life. Clearly, family members "are the most important players in the search for ways and means to improve the quality of life, the safety, the psychological and physical well-being of elderly people" (Departments of Community

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Health of the Montreal General Hospital and Verdun General Hospital, 1991). If the Jewish community is to respond adequately to the growing and changing needs of the elderly, it must take into account the needs of the family caregiver. This article presents the findings of a report on the expressed needs of family caregivers of frail elderly living in Montreal.

#### **DEMOGRAPHICS OF THE MONTREAL JEWISH COMMUNITY**

The size of the Montreal Jewish community has declined since the mid-1970s because of a decrease in the birth rate and the steady out-migration of individuals predominantly between the ages of 15 and 44 (Shahar, 1991). Projections indicate that its population will diminish by an additional 6% over the next 5 years, resulting in a total population of about 85,000 by 1996 (Shahar, 1991).

The elderly are the only segment of the population that has continued to grow over the last 10 years. In 1971, those over the age of 65 represented 14% of the Jewish population; 15 years later, that proportion increased to 21%, and it is anticipated to remain at this level through 1996. The 65-year-and-older group will continue to be a large one in the next century as the Baby Boom cohort ages (Shahar, 1991). More important is the predicted increase in the number of individuals over 75 years of age—from 40.7% of the elderly population in 1986 to 57.0% by 2001 (Shahar, 1991).

#### **NEEDS OF CAREGIVERS: REVIEW OF THE LITERATURE**

The growing body of research on caregiving has begun to reflect society's increasing recognition of caregivers' important but highly stressful role in caring for frail and disabled persons. Major sources of support for family caregivers have been identified, including informal social support (Baumgarten, 1990; Mace & Rabins, 1981; Ory et al., 1985) and the formal social service system

(Aronson & Lipkowitz, 1981; Caserta et al., 1987; Litwak, 1985).

Of the variables that potentially mediate stress, social support has been studied most intensively (Baillie et al., 1988; Baumgarten, 1990; Stone et al., 1987). "Caregivers who are caring for a mentally impaired elder, who have been providing care for an extended period of time and who have low social support are at increased risk for psychological distress or depression" (Baillie et al., 1988). One study found that caregivers who indicated they needed more social support had a lower sense of well-being than those who reported having enough social support (George & Gwyther, 1956). Zarit et al. (1980) found that the frequency of family visits to an elder person was inversely related to the caregiver burden (Baillie et al., 1988).

Informal social support in the form of family and/or friend contact continues to be one of the most important indicators of caregiver well-being. However, because of the time constraints of caregiving, caregivers are more vulnerable to increased isolation and loneliness. In fact, it has been stated that the "caregiver's dilemma constitutes a need for more support from friends and family, but less time to seek it" (Burden, 1989).

Use of formal social services can be an important aid to caregivers (Caserta et al., 1987; Soldo & Myllyluoma, 1983). Increasingly, research is exploring the effects of the use of formal services on caregiver stress. Many studies have reported the effectiveness of day care and homemaker programs in supplementing family care (Baumgarten, 1990; Caserta et al., 1987; Fengler & Goodrich, 1979; Mace & Rabins, 1984; Rathbone-McCuan, 1976; Snyder & Keefe, 1985).

Despite the benefits of using formal services, service utilization by caregivers has been very low, even when "caregiver need is beyond what their informal support network can provide" (Alzheimer's Society of Montreal, 1991). Many reasons have been

postulated for this low usage, including an inability to identify need (Baumgarten, 1990), fear of separation (Baumgarten, 1990), previous bad experiences (Alzheimer's Society of Montreal, 1991), and the limited availability of services (Mace & Rabins, 1984). Problems with access have also been used to explain the relatively low use of formal services. Caregivers seem to have a difficult time gaining access to appropriate resources even after expressing a need for them (Aronson & Lipkowitz, 1981; Ory et al., 1985; Zarit & Zarit, 1982). Gaps therefore exist between service availability and utilization (Alzheimer's Society of Montreal, 1991; Caserta et al., 1987; Snyder & Keefe, 1985).

### MONTREAL STUDY OF CAREGIVER NEEDS

#### Method

This study used an exploratory design in which caregivers — close family members and friends of frail elderly individuals residing in the community or living in an institutional setting — were asked to complete both closed-ended measures and to answer open-ended questions. They were asked to assess (1) the physical and cognitive abilities of the care-receiver using the functional status subscale of the OARS Multidimensional Functional Assessment Questionnaire (Pfeiffer, 1976); (2) their own sense of burden using the Novak Caregiver Experience Inventory (Novak & Guest, 1989); (3) their ability to cope using the Olson Family Crisis Oriented Personal Evaluation Scale (Olson et al., 1982); (4) their satisfaction with life using the OARS Life Satisfaction Subscale (Pfeiffer, 1976); (5) the existence of informal support using the OARS Social Resources Subscale (Pfeiffer, 1976); (6) their use of formal services using a scale developed by Baumgarten (Baumgarten, 1990); and (7) additional service needs using a Needs Assessment Protocol (Duder, personal communication); demographic data were also requested. All caregivers in-

terviewed in the sample were self-selected. For all scale measures, the sum of the individual items was calculated. Frequencies were calculated to describe the subjects' demographic characteristics and expressed additional service needs. Cross-tabulations were performed to compare caregivers for the variables of age, relationship to care-receiver, ethnicity, and gender across all scales. Pearson chi-square scores were used to test for significance levels. A score of  $p < .05$  determined significance.

The research study was administered by Jewish Support Services for the Elderly of Montreal (JSSE), a multidisciplinary community-based agency with the mission of meeting the needs of the frail elderly in the community in order to promote independent living and quality of life for those individuals and their families. JSSE was founded in 1988 by the Montreal Jewish federation.

#### Study Results

The caregiver experience is both varied and complex. Although most felt there were positive and reaffirming aspects to the role, more than one-third of the 86 caregivers interviewed for this study expressed feelings of stress, depression, and guilt, and over 10% expressed fear of the future. Life satisfaction scores were significantly low for over 40% of caregivers, and a small minority (3.5%) expressed fear that abuse was imminent or they were already in abusive situations with their care-receivers.

The caregivers were caring for care-receivers with some difficult problems, with a predominance of dementia-related illnesses (51.2%), including Alzheimer's disease (14.6%), stroke (13.4%), and dementia disorders (9.8%). Caregivers were responsible for helping the care-receiver with many tasks, especially those related to instrumental activities of daily living, such as using the telephone, getting to places out of walking distance, shopping, preparing meals, housework, taking medication, and handling money. These tasks required that caregivers were ever-present to monitor the

welfare of the care-receiver. Many (72.8%) could not leave the care-receiver alone for any length of time. In addition, more than half of the caregivers had no one to help them perform the activities of daily living, including helping the care-receiver eat, get dressed, walk, get in or out of bed, take a bath or shower, or get to the toilet on time. Caregivers of institutionalized care-receivers stated that they felt they must be present during meals and to respond to the emotional needs of their family member.

It has also been suggested that caregiver stress can cause or exacerbate physical ailments and illnesses in the caregiver (Baumgarten et al., 1989). Indeed, almost half the respondents stated that they had an illness or other ailments. This "other" category included nonspecific physical symptomatology, such as headaches, backaches, and dizziness.

Isolation was a significant problem for the caregivers. Almost 27% had few social resources, and 46.5% did not actively seek out social support when facing problems. One reason given for not seeking social support was that caregivers had no one to go to for help. Participation in recreational activities, including exercise and hobbies, was also low — 41.9%.

Almost half of the caregivers mentioned feeling isolated from family and friends. Over 8% expressed disappointment in the lack of involvement of their children. Given that almost 40% of the caregivers' children lived out of town and 19.7% were under the age of 20, this statement is not unexpected. Although one-third of the caregivers mentioned that children did visit the care-receiver, almost half of those visits were once a month or less.

Older caregivers seemed to have more difficulty than younger caregivers with their caregiving role. Their burden scores were higher and their satisfaction with life lower than that of younger caregivers. For example, 54.5% of those 70 and over had a low life satisfaction compared with 25.0% of those aged 50-59 and 22.2% of those aged under 49. As well, older caregivers

were significantly more socially isolated than younger caregivers.

Sephardi caregivers felt significantly more physical, social, and emotional burden than did Ashkenazi caregivers — 63.3% to 20.3% for the Physical Burden subscale; 18.2% to 3.1% for the Social Burden Subscales; and 27.3% to 7.8% for the Emotional Burden Subscales, respectively. Sephardi caregivers were also significantly more isolated than Ashkenazi caregivers — 72.7% of Sephardi caregivers were severely to totally socially impaired compared with 18.7% of Ashkenazi caregivers according to the Social Resources Scale. During times of crisis, Sephardi caregivers sought out spiritual support more often than Ashkenazi caregivers (27.3% compared to 6.2%).

Despite the existence of a variety of community services, the majority of caregivers interviewed for this study (75.4%) did not often make use of them. This corroborates results of other studies that found that caregivers underutilize formal services for a variety of reasons (Baumgarten, 1990; Mace & Rabins, 1984). Such reasons may include the lack of awareness of availability of a particular resource, a refusal to accept help, previous dissatisfaction with services, unavailability of services, and an inability to gain access to services. For example, 91.8% of caregivers were not using respite services although 25.6% mentioned they needed that service. In this study, lack of information about formal services seems to be the major barrier to access.

Many caregivers expressed a desire for additional services for the care-receiver, including counseling (25.2%), friendly visitors (31.4%), assisted transportation (34.9%), day centers (10.3%), homemaker services (16.3%), and respite care (25.6%). Respite care was particularly desired during the winter months when they were more confined to their home. Yet, very few caregivers were making use of these services, primarily because they did not know how to gain access to them. For example, 44.8% and 35.3% of respondents did not know how to obtain respite services or day

center care, respectively.

In times of crisis older caregivers were less able to gain access to community resources than younger caregivers — 31.8% of those 70+ and 38.5% of those 60-69 scored low on the Mobilizing Resources Scale compared to 6.2% of those aged 50-59 and 16.7% of those under 49. However, there was no significant difference in the ability to gain access to respite services across all age groups.

There were also significant differences between Sephardi and Ashkenazi caregivers in the ability to gain access to formal services. Ashkenazi caregivers were significantly more likely than Sephardi caregivers to know how to gain access to a homemaker or cleaning person (84.1% versus 54.6%), day hospital (67.7% versus 27.3%), and recreational activities for the caregiver (76.6% versus 27.3%). For both older and Sephardi caregivers, barriers to access include lack of experience and less opportunity to have worked in the system, lack of knowledge about the formal system, and cultural and linguistic barriers.

Despite the fact that over 33.0% of respondents were university educated and had a professional employment status, 56.7% had incomes under \$25,000 and 18.9% had incomes under \$10,000. This may reflect the decline in income status that people experience after retirement. As a result, many caregivers expressed financial concerns around their caregiving role. Almost 28% mentioned money as their most serious problem. Sephardi caregivers were particularly concerned about the lack of funds (63.6%). Financial constraints of caregiving have often been documented as a major source of stress (Ward, 1990). One negative outcome of financial strain is premature institutionalization of the care-receiver.

#### **Limitations of this Study and Future Research Areas**

The major limitation to the present study is its method of sample identification. Most

caregivers (64.0%) referred themselves for participation on the basis of information they received from pamphlets and advertising done in the community. This self-referral process biases the sample in favor of less isolated, less burdened caregivers who have experience working within the system. This bias is reflected in the large number of caregivers who are university educated and have a professional working status. Further studies may attempt to obtain a larger random sampling procedure for more accurate representation.

Most Sephardi caregivers interviewed (72.7%) were referred by social service agencies and organizations in the community. This may bias the Sephardi sample in favor of more stressed, more isolated caregivers who are in fact already in the system. Although Sephardi caregivers were predominantly French speaking, validated French instruments were not available. Comparisons between Sephardi and Ashkenazi caregivers, although still valid, may thus be limited in their generalizability. Special attention to the varying needs of these groups is important for future studies.

The majority of respondents were born in Canada (62.4%), suggesting that the study is missing the large group of Holocaust survivors and immigrants who might not know how to gain access to the system as well as others. This was corroborated by the fact that 70% of respondents had English as their mother tongue.

Despite the existence of many studies highlighting the differences between male and female caregivers (Brody, 1981; Fengler et al., 1979; Meier Robinson, 1989, no significant differences were found in this study. Further research in this area is required.

#### **DISCUSSION**

The research provides a strong argument for continued and increased intervention with caregivers and their care-recipients. Given that a majority of care-receivers (51.2%)

had dementia-related disorders or diseases, the fact that over 20% of caregivers did not have anyone to help them with instrumental activities of daily living is a cause for concern. Stress and isolation have been expressed by caregivers, and it has been suggested in the literature that very high stress and/or burnout can lead to elder abuse (King, 1983). Some caregivers (3.5%) interviewed for the study did abuse their care-receiver or were afraid of becoming abusive.

Intervention in support of caregivers and their families must come from several levels. Both the public and private sector must commit themselves to improving and increasing services to care-recipients and their families. With this comes the need for increased recognition of the difficult role of the caregiver. Caregivers have stated that financial problems may result in premature institutionalization of the care-receiver, which not only costs the government more in monetary terms but also detrimentally affects the care-recipient and family. Premature institutionalization leads to more rapid deterioration of the frail elder (Newman et al., 1990). Support to caregivers in the form of financial compensation (i.e., tax credits) is an important consideration. Other areas for government assistance include more accessible community health services, such as homemakers, day centers, respite options, ongoing counseling, and assisted transportation for frail seniors and their families.

Community-based organizations can do much to improve the well-being of the caregiver by providing the following services:

- family counseling/meetings to help bring children and other family members into the caring process to alleviate some of the strain on primary caregivers
- advocacy to help caregivers maneuver through the system so that they can achieve some much-needed personal time with which to pursue social contacts and recreation
- support groups and ongoing counseling to help caregivers deal with the many stresses and concerns of caregiving
- friendly visitors, telephone buddies, and volunteer drivers
- advocacy on behalf of the frail elderly and their families to the health and social service sector, to a larger society, and to the government to ensure that the services received by the frail elderly and their families meet the standards and reflect the true needs of those who are primarily responsible for the care of these members of our community — the family caregiver

Communal and social service professionals must be educated to help the caregiver in a variety of ways. For example, they should offer compassion and support, help caregivers locate and obtain appropriate resources, and be sensitive to cultural and linguistic differences. Caregivers often mentioned that workers from Jewish and other non-profit organizations and institutions were not sensitive to their cultural needs. Health and social service professionals need to learn to “look behind the wheelchair” to the needs of the family caregiver; training programs should be designed to increase their sensitivity to caregiver needs.

One of the reasons that caregivers underutilize services is the lack of information about them (Aronson & Lipkowitz, 1981). Caregivers who are Canadian born and well educated are traditionally considered more able to obtain resources. The reality is that they too are having trouble maneuvering through the system. In the present study a large number of caregivers would not know how to obtain particular services even if they needed them. Therefore, ongoing outreach and education must be primary goals so that caregivers become more aware of the resources available to them.

Special interest must be paid to two groups who have been identified in the research as having particular difficulty obtain-

ing resources — older caregivers and Jewish caregivers of Sephardi origin. Both groups reported a higher sense of burden in some areas, a lower number of social resources, and less knowledge about community resources. Specific outreach/educational programs targeting both older caregivers and/or Sephardi caregivers would be beneficial for facilitating the entry of these caregivers into the formal network. For caregivers of Sephardi origin, synagogues can be used as a means of outreach and education as Sephardi caregivers interviewed indicated that they received positive support from their involvement in religious institutions.

### CONCLUSION

As the population ages, the search for ways and means to provide caregivers of the frail elderly with sensitive and adequate support is becoming increasingly important. Without formal support from the community, individuals will not be able to continue to provide care to their frail elderly relatives in a way that maintains their own health and well-being. In the present study, caregivers have expressed that a plethora of services are needed to support both themselves and their loved ones on a daily basis. Health and social service providers must become involved in the planning and implementation of such services to ensure that caregivers are well equipped to deal with the emotional, psychological, and physical tasks of being a care provider, without jeopardizing their own health or the health of their loved ones. In addition, family caregivers must be helped in their efforts to unravel the complex system of health and social services and must be continuously involved in the evaluation of such services if we are to respond most effectively to the needs of the frail elderly and their families in our community.

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