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## **Elderly People with Dementia: Prevalence, Identification of Unmet Needs and Priorities in the Development of Services**

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# **Executive Summary**

## **1. Background and Study Goals**

Today, people are living longer lives. As a result, age-related conditions have begun to pose a significant challenge to health and welfare services. One of the most severe of these is dementia, which is characterized by a decline in memory and other cognitive functions, which leads to a decline in intellectual ability and daily functioning. This condition has a devastating effect on those who suffer from it, on the family who care for them, and on society.

This study provides information on the prevalence of dementia among elderly people age 65 and over living in the community in Israel, on the characteristics of elderly people with dementia, and on the characteristics of their family caregivers. Data on the prevalence of dementia can be used in planning at the national level in the present, and to forecast the prevalence of dementia in the future, following changes in the socio-demographic characteristics of the elderly. This study also provides information on the need for health and welfare services of people with dementia and their families, and on the gap between these needs and existing responses to them. It is hoped that such information will be used to improve existing services and facilitate judicious planning of community services that are adapted to the needs of the elderly and their families. To date, information about the topics covered by this study has been lacking in Israel.

The study's uniqueness arises from its being the first comprehensive study in Israel to examine the extent of dementia among elderly living in the community, the extent to which these people are known to the system of services, and the extent of their and their families' unmet needs. It was conducted in multiple stages, and included an in-depth clinical examination that was meant not only to identify the overall prevalence of dementia, but also to distinguish among its levels of severity. Thus, for the first time, this study provides an estimate of the size of the population suffering from the early stages of dementia. Elderly in the early stages of the condition, and their families, are now recognized as being a very important target group for early intervention programs, which can not only help slow the pace of the disease but also make available supportive services that will reduce burden on the family, and prepare those with dementia and their families for the later stages of the disease.

## **2. The Study Design and Data Collection**

The study's target population included elderly people age 65 and over living in the community in Jerusalem and Kiryat Gat, based on lists of the Ministry of the Interior for August 2000 (exclusive of the Arab population).

The study focused primarily on the elderly population in Jerusalem, such that our estimates of the prevalence of dementia are based on the data for Jerusalem. Jerusalem's population is heterogeneous, representing groups with different socio-demographic characteristics. The city of Kiryat Gat, which differs from Jerusalem, was also included in the study. Kiryat Gat is smaller than

Jerusalem, located to the south of it in a less populous area, and offers a smaller and less varied supply of health and welfare services. The inclusion of Kiryat Gat in the study thus enabled us to learn about the unmet needs of the elderly in a peripheral area.

The study's target population comprised 52,428 elderly people in all: 47,834 in Jerusalem and 4,594 in Kiryat Gat. We conducted a random sample in each city separately, according to gender strata and five age groups. The sample population numbered 2,425 elderly people: 1,624 in Jerusalem (or 3.4% of the elderly population there) and 804 in Kiryat Gat (17.4% of the elderly population there). Data collection began in December 2000 and ended in December 2002.

The study was conducted in three stages: (1) initial screening, (2) clinical evaluation, and (3) needs assessment.

- (1) **Initial screening** was conducted using face-to-face interviews with the elderly person and a member of his or her family; its aim was to identify elderly who were suspected of suffering from dementia. During this stage, interviews were conducted with 1,577 elderly people (65% of the original sample) and 1,394 family members. Information on the cognitive status, functional status, and behavior of the elderly was collected using accepted and validated research tools. Cognitive status was examined using the Modified Mini-Mental State Exam ("3MS"); elderly people whose score was under 78 – indicating a significant deterioration in cognition – were included in the subsequent clinical evaluation. In all, 493 elderly people (31% of those interviewed during this stage) were included in the clinical evaluation stage.
- (2) **Clinical evaluation.** The elderly were asked to undergo a clinical examination to assess their neuro-behavioral and cognitive status, using a protocol developed by the Neuro-psychogeriatric Department of Herzog Hospital (Wertman, 2000), in accordance with the diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders, Third and Fourth Editions (DSM-III-R and DSM-IV). At this stage, it was determined whether the elderly person was indeed suffering from dementia, and if so, at what level of severity. The clinical examination was conducted in the home of the elderly person by a team of physicians comprising specialists in neurology, behavioral neurology, or neuro-psychology. In addition, a multi-professional staff used the information collected during the initial screening and the results of the clinical examination to try and reach a consensual diagnostic opinion on each elderly individual. In effect, 331 elderly people (67% of those included in the clinical evaluation) underwent a clinical examination; 255 (77%) of them were diagnosed with dementia.
- (3) **Needs assessment.** Interviews were conducted with the primary informal caregivers of those elderly people diagnosed with dementia. The interviews were meant to reveal the extent and type of care they provided to the elderly, their needs and those of the elderly for services, and the degree to which the system of services responds to their needs. During this third stage of the study, interviews were conducted with 186 caregivers of the 255 elderly people diagnosed with dementia.

At each and every stage of the study, every effort was made to prevent the loss of cases (i.e. dropout). However, because of the nature and complexity of the study, a certain rate of dropout was

noted at each stage. The main reason for dropout during the initial screening stage was refusal of elderly to participate. The main reason for dropout during the clinical evaluation stage was refusal to be examined, either by the elderly person or his family. The main reasons for dropout during the needs assessment stage were that the elderly person had died or been transferred to an institution between the date of diagnosis and the date of the interview.

Due to case dropout, we examined the representativeness of the sample at each stage of the study using the parameters we had used to conduct the original sampling – that is, gender, and five age groups. We found that the dropout cases were distributed among the various strata. During the data analysis stage, we weighted the remaining cases according to the sampling strata, to ensure that they would be representative of the elderly living in the community in the two cities.

Ideally, we would have liked the study's target population to include all people age 65 and over living in the community in Israel. However, it was not possible to conduct a national sample of all of the elderly in Israel and then interview and examine them, because of the high cost involved, and logistical difficulties arising from the geographic dispersal of the population. Therefore, we chose to study the prevalence of dementia and the needs of those with dementia and their families in depth, in two cities. This approach is not unique to this study. Epidemiological studies have been conducted among distinct populations in specific geographic areas (e.g., a neighborhood of a large city, one or more regions, one or more cities), and their findings statistically applied to the total population (see Rosso et al., 2003; Herbert et al., 2003; Massachusetts Alzheimer's Association, 2002; Medical Research Council, 1998).

### **3. Findings**

#### **The Prevalence of Dementia among People Age 65 and Over in Jerusalem, by Selected Characteristics**

- ♦ As noted, we estimated the prevalence of dementia among elderly age 65 and over living in the community in Jerusalem, who comprised the majority (92%) of the study population. We found that 19.2% of them had some level of dementia, 8.2% had mild dementia, 4.4% had moderate dementia, and 5.8% had severe dementia (no level of severity was determined for 0.8% of the elderly with dementia).
- ♦ As expected, the percentage of those with dementia living in the community in Jerusalem increases with age, such that 47% of those age 85 and over were found to have the condition, compared to 11% of those ages 65-74.
- ♦ We also examined the prevalence of dementia among elderly living in the community in Jerusalem according to additional characteristics: 22% of the women had dementia, compared to 16% of the men; 60% of those with limited (0-4 years) education had dementia, compared to 7% of those with post-secondary education; and 34% of those born in Asia or Africa had dementia, compared to 17% of those born in the former Soviet Union and 13% of those born in Europe, America or Israel.
- ♦ A multivariate logistic regression analysis conducted on the elderly living in the community in Jerusalem revealed that older age and lower education had the greatest independent effect on the

probability of having dementia. Continent of origin was also found to have an effect, if a lesser one, while gender had no independent effect when controlling for age, gender and origin.

- ♦ Some elderly with dementia do not live in the community, but in long-term care institutions. Therefore, in an attempt to estimate the prevalence rate of dementia among the total elderly population in Jerusalem, we used data from a study (conducted in 1999 in cooperation with the authors of the current study) of the prevalence of dementia among elderly age 65 and over in long-term-care institutions in Jerusalem (Feldman et al., 2004). It indicated that 70% of these elderly had dementia, at all levels of severity.
- ♦ When we applied the specific rates of those with dementia living in the community and in institutions in Jerusalem by gender and all age groups to data on the total Jewish elderly population in Jerusalem at the end of 1999, we found that 21.7% of all of the elderly in Jerusalem were suffering from dementia.
- ♦ Examination of the rate of those age 65 and over with dementia in Jerusalem by type of residence revealed that 84% were living in the community and 16% were in institutions.
- ♦ In order to arrive at a national estimate of the prevalence of dementia, we applied the specific rates of elderly with dementia in the community and institutions in Jerusalem by gender and all age groups to data on the total Jewish elderly population in the community and institutions in Israel at the end of 2002. We found the prevalence of dementia among those age 65 and over living in the community in Israel was an estimated 16.7% (some 98,000 individuals). Of them, 7.3% (about 43,000 people) had mild dementia, 3.8% (22,000 people) had moderate dementia, and 4.7% (27.5,000 people) had severe dementia. We were not able to assess the severity of the condition of 0.9% of those with dementia. An estimate of the prevalence of dementia among those age 65 and over in both the community and institutions reached 19.1% (some 117,000 people).
- ♦ Close to half of the elderly living in the community who had dementia were in the initial stages of the condition.
- ♦ The percentage of people age 65 and over in Israel found by this study to have dementia was at the top of the range of rates quoted in meta-analytic studies. For example, Ineichen (1987) examined a number of studies and found that the prevalence of dementia ranged between 2.5% and 24.6%. The prevalence rate of various levels of severity of dementia found by this study was within the range of rates quoted by meta-analytic studies (see Henderson, 1994; Jorm et al., 1987; Henderson, 1986).

### **Characteristics of Elderly Age 65 and Over with Dementia Living in the Community in Jerusalem and Kiryat Gat**

- ♦ **Functional status:** Fifty-four percent were disabled in at least one personal-care activity (ADL), although the percentage differed according to the severity of the disease. Disability rates increased with the rise in the severity of the disease (33%, 56% and 85% for mild, moderate and severe dementia, respectively). In addition, 67% were totally dependent in their capacity to perform instrumental activities of daily living; this percentage was highest among those with severe dementia (98%, as compared to 56% and 57% for mild and moderate dementia, respectively).

- ♦ **Mobility:** Fifty-eight percent were limited in mobility outside the home; the percentage rose to 86% among those with severe dementia. Fifteen percent were limited in mobility inside the home; the percentage rose to 47% among those with severe dementia.
- ♦ **Behavioral disturbances, memory problems and emotional state:** None of the ten behavioral disturbances included in the Neuro-psychiatric Inventory (NPI) were found among 21% of the elderly. However, five or more disturbances were found among one-fifth (10%) of them. The number of disturbances increased with the severity of the disease: 15% of those with mild dementia suffered from five or more disturbances, compared to 20% and 25% of those with moderate and severe dementia, respectively.
  - Two-thirds (63%) of the family caregivers interviewed reported that their elderly relative had memory problems; this percentage increased as the severity of the disease increased (36%, 77% and 84% for mild, moderate and severe dementia, respectively). In other words, 37% of the family caregivers of an elderly person with dementia were not aware that their family member had a memory problem.
  - One-fifth (20%) of the family caregivers reported that they had already been told by a physician that their elderly relative had dementia or Alzheimer's Disease. This percentage also increased with the severity of the condition, from 7% of caregivers of a person with mild dementia and 19% of caregivers with moderate dementia to 42% of caregivers of a person with severe dementia. This suggests that a considerable proportion of the elderly who were diagnosed by this study as having dementia – including those with severe dementia – had not previously been diagnosed.
  - Sixty-three percent of those with dementia displayed symptoms of depression according to the Geriatric Depression Scale (GDS), a tool used to screen for signs of depression.
- ♦ **The need for supervision:** According to family caregivers, nearly half (46%) of the elderly with dementia could be left home alone for an entire day (eight or more hours). However, this rate declined with an increase in the severity of the disease (69%, 45% and 7% of people with mild, moderate and severe dementia, respectively). One-third (33%) of the elderly with dementia could be left alone for part of the day (15% for at least three hours and 18% for less than three hours), but one-fifth (21%) of them required constant supervision and could not be left home alone at all. The percentage rose to 53% among those with severe dementia.
- ♦ **Health status:** Ninety-five percent of the elderly with dementia had at least one other chronic condition. Thirty percent had five or more additional chronic conditions, among them heart disease (29%), constipation (53%), vision problems (56%) and sleep-related problems (55%). These data suggest the complexity of caring for patients with dementia.

### **Use of Long-term Care, Welfare and Health Services, and Unmet Needs**

We gathered information regarding the patterns of use of long-term care and social and health services of elderly with dementia, as well as their unmet needs, from their primary informal caregivers, most of whom were family members.

- ♦ **The Community Long-Term Care Insurance (CLTCI) Law:** Over half (56%) of those suffering from dementia were receiving assistance under this law, which is administered by the National Insurance Institute. The rate rose to 79% among those with severe dementia, compared to 65%

and 41% among those with moderate and mild dementia, respectively. The percentage of those receiving assistance under the law was higher when the person had a functional disability. Thus, 83% of those disabled in at least one ADL and 92% of those disabled in all ADLs were receiving assistance under the CLTCI Law. Eight percent of the family caregivers of elderly persons with dementia reported having petitioned the National Insurance Institute for assistance but having had their petition denied. (We have no information as to the reason; it is possible that some applicants failed to pass the means test.) Another 30% of the caregivers reported never having asked for assistance under the CLTCI Law, primarily because their elderly relative "did not need help and could manage alone or with the help of his family". Among those elderly who did have a personal-care aide, one-third (31%) had the personal-care aide for 24 hours a day. In other words, 18% of all elderly with dementia had a 24-hour personal-care aide.

Forty five percent of the family caregivers reported that their elderly relative needed more assistance from a personal-care aide: 30% needed additional hours of assistance from a personal-care aide and 15% did not have an aide but needed one. The percentage of those needing more hours of assistance from a personal-care aide was greater among elderly with severe dementia (48%, compared to 33% and 17% among those with moderate and mild dementia, respectively). The percentage of those who had no personal-care aide but who needed one was greater among elderly with mild and moderate than with severe dementia (22%, 20% and 2%, respectively).

- ♦ ***Visits to a social framework:*** Twenty-six percent of the elderly with dementia visited a social framework such as a senior club or day care center during the three months preceding the interview. The percentage was much greater among those with mild and moderate dementia than among those with severe dementia (29%, 33% and 7%, respectively). Further, 40% did not visit a social framework though their family members felt they should. This was more true of those suffering from mild or moderate dementia than of those suffering from severe dementia (46%, 42% and 29%, respectively).
- ♦ ***Contact with a social worker:*** Forty-one percent of the elderly had met with a social worker during the past year. Thirty-two percent of the family caregivers of those who had not (i.e. 18% of all elderly) felt that their elderly relative should have such contact.
- ♦ ***Home visits from a volunteer:*** A volunteer visited only 6% of those suffering from dementia; 50% of the family caregivers reported being interested in having their elderly relative receive such visits.
- ♦ ***Emergency call button:*** Forty-one percent of the elderly had an emergency call button which was linked to an outside call center; the rate was higher among those with mild and moderate dementia than among those with severe dementia (44%, 52% and 26%, respectively). Seventeen percent of the elderly did not have an emergency call button, though their family caregiver thought they should.
- ♦ ***Use of primary medical services:*** Ninety-six percent of the elderly had met with their family physician during the past year. However, 11% of those with severe dementia had not had contact with a family physician during the past year. In addition, 11% of the family caregivers reported that their elderly relative had needed the family physician to make a house call during the past year, but that the physician had not done so. Eighty-two percent of the elderly had met with primary care clinic nurse during the past year. Seven percent of the family caregivers

reported that their elderly relative had needed the nurse to make a house call during the past year, but that she had not done so.

- ♦ **Visits to private physicians and specialists:** Twenty percent of the elderly had visited a private physician during the past year. The percentage increased with the increase in the severity of the disease (10%, 21% and 41% of those with mild, moderate and severe dementia, respectively). In addition, 13% had seen a psychiatrist and 23% had seen a neurologist during the past year.
- ♦ **Paramedical services:** Thirty percent of the elderly had undergone physiotherapy, 5% had undergone occupational therapy and 11% had seen a nutritionist during the past year. In addition, the family caregivers believed that their elderly relative needed but had not received physiotherapy (30%), occupational therapy (27%), or the intervention of a nutritionist (20%).
- ♦ **Use of hospital services:** Thirty percent of the elderly had been hospitalized during the past six months and 25% of them had visited the emergency room during the past six months, but were not admitted to the hospital. These rates were greater than those for the overall elderly population in Israel as reported by the Central Bureau of Statistics (1997), which found that 15% of the elderly had been hospitalized and 19% had visited the emergency room.
- ♦ **Vision and hearing tests:** Sixty-two percent of the elderly with dementia had had their vision tested during the past year, although 26% of those who had vision problems had not had their vision tested during this time. Twenty-six percent of the elderly with dementia had had a hearing test during the past year, though nearly half (46%) of them had never had a hearing test. Also, two-thirds (65%) of those with hearing problems had not had a hearing test during the past year.
- ♦ **Dental care:** Twenty-nine percent of the elderly had visited a dentist during the past year. However, 63% of those who had problems with their dentures had not visited a dentist during this period.
- ♦ **Use of medications:** Ninety-five percent of those with dementia were taking prescription medications, but only 4% were taking medication aimed at slowing the progress of dementia. One-third (35%) of the family caregivers reported that there were problems with the medications their elderly relative was taking, chief among these being their high cost.

#### **Data on the Primary Informal Caregivers of Elderly Persons with Dementia**

- ♦ **Demographic characteristics:** Most (97%) of the caregivers were members of the elderly person's family, mainly his or her spouse (27%), or son or daughter (62%). Sixty percent of them were women. Their average age was 54.8; 33% were age 65 or over, and 14% were age 75 and over. Forty-three percent of them were living with their elderly relative.
- ♦ **Physical and mental health:** Forty-one percent of the caregivers defined their own health condition as being fair or poor. Thirty-six percent of them were found to be at risk for depression according to the Center for Epidemiologic Studies Depression Scale (CES-D).
- ♦ **The assistance provided by caregivers:** Thirty-seven percent of the caregivers reported providing personal-care assistance (e.g. dressing, bathing, feeding). This percentage increased with the increase in the severity of the disease (25%, 40% and 65% among elderly with mild, moderate and severe dementia, respectively). Although most of them found it difficult to assess the exact number of hours they devoted to personal care, about half of them reported devoting "many hours" to it, or helping "all day long – 24 hours a day" (20% and 31%, respectively); the



percentages were greater among those caring for elderly with severe dementia (71%) and those living with the elderly person (69%). Nearly two-thirds (63%) of those who did not live with the elderly person reported helping with household chores (e.g., cleaning, doing laundry, cooking or shopping) and 86% reported helping with instrumental activities, such as escorting and driving the elderly person, picking up medications, and managing the elderly person's finances.

- ♦ ***The burden on caregivers:*** Forty percent of the caregivers reported that there was no other unpaid person helping them care for their elderly relative; 34% had no one who could replace them even temporarily if they wanted to take a vacation; and 38% reported that the burden they bore was very heavy or heavy. The percentage was even greater among those who cared for an elderly person with severe dementia (52%), an elderly person disabled in three or more activities of daily living (ADL) (59%), or an elderly person with behavioral disturbances (53%). Moreover, 61% of those who lived with their elderly relative reported that the burden they carried was very heavy or heavy. Thirty-eight percent said that the patient's condition would make it difficult for them to take even a short vacation; the percentage rose to 58% among those caring for elderly with severe dementia.
- ♦ ***The effect of caregiving on financial status:*** Twenty-six percent of the caregivers who were employed said that they had to work fewer hours than they would like; the percentage rose to 46% of those caring for elderly persons with severe dementia. Furthermore, 75% of the caregivers reported having had non-refundable expenses arising from caregiving during the past month.
- ♦ ***Respite care:*** Thirty-three percent of the caregivers expressed a need to take time off from caring for their relative; the percentage increased with the severity of the disease (20%, 43% and 54% of those caring for elderly with mild, moderate and severe dementia, respectively). Twenty-nine percent reported that they would use a respite care service if it were available; the percentages were greater among those caring for an elderly person with severe dementia (51%), an elderly person who was also disabled in ADL or had behavioral disturbances (41%), and among those living with the elderly person (38%).
- ♦ ***The unmet needs of caregivers:*** The caregivers reported unmet needs for a broad range of services, notably for information and counseling on caring for an elderly person with dementia. For example, 51% of the caregivers who reported that their relative had memory problems expressed an interest in receiving information on how to deal with those problems and how to improve their relative's memory capacity, and 29% of the caregivers who reported that their relative had behavior problems expressed an interest in receiving information and guidance on how to deal with those problems. The need for information and guidance was more prevalent among caregivers of elderly persons with mild and moderate dementia than among those caring for relatives with severe dementia. Also, 70% of the caregivers reported not receiving enough information about relevant community services that could be of benefit to them and their elderly relative. Not one of the caregivers had participated in a support group, although one-third of them said they would like to do so.
- ♦ ***Transferring the elderly person to an institution:*** About one-fifth (20%) of the caregivers had considered transferring their elderly relative to an institution (e.g., an old-age home, nursing home or hospital for the chronically ill). The rate was higher among those caring for an elderly

person over age 75, an elderly person disabled in ADL, or an elderly person with behavioral disturbances. Interestingly, more caregivers of elderly persons with moderate dementia had considered this possibility than had caregivers of elderly persons with mild or severe dementia (34%, versus 15% and 21%, respectively). It is possible that those caring for an elderly person with mild dementia had yet to experience significant difficulties, while those caring for an elderly person with severe dementia had become accustomed to their condition.

### **Patterns of Service Use and Unmet Needs, by City**

As noted, the study was conducted in two cities – Jerusalem and Kiryat Gat. As expected, the findings indicated differences between the two in use of services and in the unmet needs of the elderly and their families.

- ♦ Seventy-seven percent of the elderly with dementia in Kiryat Gat and 52% of those in Jerusalem were receiving assistance under the CLTCI Law. One explanation for this gap is that the percentage of those disabled in personal-care activities (ADL) was greater in Kiryat Gat than in Jerusalem (69% versus 55%, respectively).
- ♦ A greater percentage of elderly in Jerusalem (31%) than in Kiryat Gat (9%) attended a social framework (e.g., senior club, day care center). Accordingly, more family caregivers in Kiryat Gat than in Jerusalem (66% and 34%, respectively) reported that they would like their elderly relative to visit such a framework. The percentage of family members who were interested in having a volunteer visit their elderly relative was also greater in Kiryat Gat than in Jerusalem (63% versus 47%, respectively).
- ♦ More elderly in Kiryat Gat than in Jerusalem needed adaptations to their home (46% versus 23%, respectively), the installation of an emergency call button (29% versus 14%, respectively), mobility aides (44% versus 23%, respectively), or medical equipment (38% versus 24%, respectively).
- ♦ A much greater percentage of family caregivers in Kiryat Gat than in Jerusalem were interested in receiving information and counseling on various topics. For example, 66% of the family caregivers in Kiryat Gat who reported that their relative had a memory problem reported an interest in information on this topic, compared to 47% of family caregivers in Jerusalem; and 27% of the family caregivers in Kiryat Gat expressed an interest in receiving legal advice, compared to 9% of the family caregivers in Jerusalem.
- ♦ About half of the family caregivers in Kiryat Gat and one-third (38%) of those in Jerusalem reported that the burden of caring for their elderly relative was very heavy or heavy; 47% of those in Kiryat Gat and 25% of those in Jerusalem expressed a willingness to use respite care services; and 50% of those in Kiryat Gat compared to 28% of those in Jerusalem reported being interested in participating in a support group.

## **4. Discussion and Policy Implications**

The findings of this study have significant implications for the development of policy and services to better meet the needs of both elderly suffering from dementia and those of their families.

## **A Need to Recognize and Diagnose Dementia**

Most of the elderly who were identified by the study as having dementia, particularly those with mild dementia, had not been diagnosed previously. The phenomenon of undetected dementia has been found to be prevalent in other countries, as well (Ross et al., 1997; Sternberg et al., 2000). Studies have found that many elderly and their families often wait a long time before seeking diagnosis and treatment from the health system (Black and LoGuidice, 2001). There are many reasons for this, among them insufficient familiarity with initial signs of dementia; anxiety and fear of the disease and its outcomes; and lack of knowledge about the existence of diagnostic, treatment and community care services, which could help the elderly and their families. It is therefore imperative to increase activity aimed at identifying elderly suspected of having dementia as early as possible, so as to ensure that they be diagnosed at an earlier stage of the disease. Many in developed countries have rallied round this message (Alzheimer's Association Australia, 2001; Alzheimer's Scotland, 2004; Duncan and Siegal, 1998; Marin et al., 2002; Relkin, 2000; Alzheimer's Association, United States, 2000).

Early diagnosis may have significant benefits not only for the elderly person, but also for his family and the professionals who care for him. In part, it would increase their awareness of the situations that may arise in the future, and for which they must prepare. For example, elderly in the early stages of dementia can still be active participants in decisionmaking about their future and that of their family, in preparation for a time when they may not be able to make decisions. The awareness that comes with early diagnosis would also enable the elderly and their families to actively seek useful information, suitable sources of supportive services, and, of course, timely medical care, and cognitive and psychosocial interventions. Moreover, evidence exists that early diagnosis can contribute to lessening the burden and anxiety felt by family members. It can also reduce the possibility of receiving expensive and inappropriate medical treatment, prevent premature institutionalization, and facilitate access to innovative medications. All of these factors would benefit not only the elderly person and his family, but also the health system and society in general, since they may reduce health-care costs by slowing the development of the disease, providing effective community care and treatment, and thereby delaying institutionalization (Audit Commission, 2000; Bird and Parslow, 2001; Relkin, 2000).

There thus appears to be a need to considerably expand activities aimed at providing information that will increase public awareness of the early signs of dementia, as well as of the diagnostic and treatment options available to the elderly and their families. To this end, it is necessary to improve available information dissemination tools and develop new ones. Many organizations should take part in this task, including formal health authorities – the Ministry of Health, the health plans (like health maintenance organizations (HMOs) in the United States) and the Ministry of Social Affairs – and NGOs such as the Alzheimer's Association of Israel; all of them have an important role to play. At present, it appears that most such activity is conducted by NGOs, which have limited resources and are finding it difficult to address the increasing demand for their services. The national-level involvement of the health plans, in particular, should be significantly increased, as most elderly tend to primarily seek help from their health plans. It is worth noting that in some

countries voluntary organizations receive government support, which allows them to provide a broad range of services.

The literature greatly emphasizes the need to increase the early detection of dementia by family physicians within the framework of primary care clinics (Black and LoGuidice, 2001; Audit Commission, 2000; Rait, Walters and Iliffe, 1999), as these are, first and foremost, the elderly person's point of entry into the medical system. Family physicians are frequently approached for help, and are seen by the elderly as an important source of information and guidance regarding their medical problems. This study revealed that nearly all elderly with dementia visited their family physician during the past year. However, this and other studies have found that in Israel and elsewhere, dementia remains undetected and hence goes undiagnosed. It is thus possible that family physicians are not doing enough to identify dementia in its earliest stages. According to the literature, some of the reasons for this are a lack of appropriate training, failure to use appropriate screening tools, a lack of awareness of the need for diagnosis by specialists and hence the need for referral to them, and a lack of awareness of existing treatments and community services (Black and LoGuidice, 2001; Rait, Walters and Illiffe, 1999; Audit Commission, 2000).

Some researchers and clinicians believe there is not enough information available to unilaterally recommend conducting cognitive screening tests for dementia among the general elderly population in the framework of primary medical care. In particular, there is a lack of information on the ability of family physicians to conduct screening tests and on the ability to provide effective care in the framework of primary medical care (Boustani et al., 2002, 2003; Costa et al., 1996; Audit Commission, 2000; Patterson and Gass, 2001). However, other researchers have concluded that family physicians should be more alert to signs such as memory loss, other cognitive problems and behavior problems, and conduct a comprehensive evaluation when a problem is identified, or else refer the patient for such an evaluation. Some studies recommend expanding screening tests to cover all elderly age 75 and over. A White Paper published in England in 1987, entitled "Promoting Better Health" (Blakeman et al., 2001; Sims et al., 2000) emphasized the importance of an annual check-up by a family physician for all elderly. Following the implementation of the contract program with British family physicians in 1990, they were required to ensure that each elderly person age 75 and over undergo a comprehensive annual examination, including a test of his mental and cognitive state (Shackley and Donald, 1993). Similarly, the Israel Medical Association has published clinical guidelines for preventive medicine and health promotion in the community, which include guidelines regarding tests for cognitive deterioration (Tabenkin, 2000).

### **The Development of Services that Will Address the Unmet Needs of Elderly with Dementia and Their Families**

The study identified unmet needs in the following areas.

***Non-professional home care:*** According to family members, many elderly with dementia require more hours of assistance than they were receiving. In an effort to improve the adequacy of services for the elderly, the National Insurance Institute has been considering changing the allocation of

hours provided to eligible clients, such that elderly with more severe levels of disability who need supervision will receive more hours of care than in the past, while those with milder disabilities will receive fewer hours of care. However, these changes have yet to be implemented, in part because many within the system object to reducing the number of hours of care provided to the less disabled elderly.

**Medical home care:** Given the complex nature of dementia and the problems it incurs, it is important to ensure regular medical follow-up every three or six months at a primary care clinic, or at home, for those who cannot reach the clinic.

**Day care frameworks:** A significant proportion of the elderly with dementia do not use frameworks such as day care centers and senior clubs, even though in many cases – particularly those in which the elderly person has mild or moderate dementia – their families would like them to do so. Day care frameworks can provide care for the elderly and engage them in activities while giving family caregivers a few hours of respite, thereby alleviating their burden. This might help enable family members to continue providing home care for a long time, in turn delaying or perhaps even preventing institutionalization (Dupuis, Epp and Smale, 2004; Dziegielewski and Ricks, 2000; Gottlieb and Johnson, 2000; Montgomery, 2002; Zarit et al., 1998). In recent years, ESHEL – The Association for the Planning and Development of Services for the Aged in Israel and other organizations have opened numerous day care centers, which include a separate unit for the mentally frail. However, these are not used to capacity, and hence could serve many more elderly. It is important to examine in depth the reasons for the under-utilization of these frameworks. At the same time, it is necessary to make the elderly and their families more aware that such frameworks exist, and that they could make a significant contribution. Furthermore, health and welfare services need to improve their information dissemination and counseling activities about the community services available to elderly with cognitive disabilities and dementia of all levels of severity.

**Respite care services:** Another service that could help alleviate the burden on families is respite care, which assumes care of the elderly person for a limited period of time. This service is almost non-existent in Israel, although many family caregivers of elderly people with severe dementia have cited a need for it. Some countries, and Australia in particular, have developed various models of this service, including an in-home respite service, host family respite care and out-of-home frameworks for vacation or emergency respite (Archibald, 1996; Dupuis et al., 2004; Montgomery, 2002). In light of current needs, these models should be carefully examined to see whether they might be applied in Israel.

**Volunteer services:** This study found that a very small percentage of elderly with dementia had been visited by a volunteer, despite the desire of half of the family caregivers that such visits take place. It therefore appears that here, too, there is a need for more information on the organizations that provide this service, concurrent with a need to encourage volunteers to support and assist the elderly and their families. To this end, it is necessary to expand frameworks that recruit, train and supervise volunteers (MacIntyre et al., 1999).

**Information and guidance:** In addition to expressing a need for more information about dementia, the importance of diagnosis, and where diagnostic testing is conducted, some family caregivers, particularly those caring for an elderly relative with mild or moderate dementia, expressed an interest in receiving information and guidance on coping with the symptoms of the disease, the problems it causes (e.g., memory loss and behavior problems), and the difficulties of caregiving. Family caregivers also expressed an interest in receiving more information about relevant community services. There therefore seems to be a need to inform the public about organizations that currently provide information and guidance, and to expand such activity in order to meet the information needs of families, so as to arm them with the skills that will help them care for their elderly relative. Education and training programs for families of elderly persons with dementia have been developed by Alzheimer's Disease Associations in other countries, with government support. For example, Alzheimer's Disease Associations in Australia are implementing the "Carers Education and Workforce Training Project" and the "Dementia Education and Support Program", targeted at dementia patients, their families, and professionals in the health and welfare service systems. In addition, a service specializing in the provision of counseling on handling behavior problems – the "National Dementia Behavior Advisory Service" – has also been developed in Australia (Alzheimer's Australia, 2004). Given the needs expressed by family caregivers in Israel, it may be wise to carefully examine these and other programs developed abroad, and consider adapting them to Israel.

**Group and individual support:** Family caregivers of elderly persons with dementia also need psychosocial support if they are to continue caregiving over time and mitigate feelings of burnout. There is thus a need to significantly increase psychosocial interventions such as support groups and individual and family counseling, which can support not only the elderly but their families as well, some of whom are themselves elderly and have health problems and diminished emotional well-being (Audit Commission, 2000; Dupuis et al., 2004). The Alzheimer's Association of Israel has recently established support groups for elderly people experiencing the early stages of dementia. This program should be studied, and an attempt made to expand it to more elderly people and their families. A service of this type could be a source of significant emotional support, and could provide tools and information on coping with the many problems that accompany dementia (McFarland et al., 1999; Yale, 2001).

**Case management for elderly with dementia and their families:** Given the complexity of dementia, its multiple symptoms and far-reaching effect on the lives of those who suffer from it and their families, the professional literature has highlighted the effectiveness of the case management approach for this population. According to this approach, a care manager would be the central "address" for people with dementia and their families throughout all stages of the disease and for all needs. A care manager would have to be able to identify those needs, identify the best solutions to them, coordinate among care providers, ensure the continuity of care and the transfer of information among care providers, monitor the patient's condition, and modify the care plan according to any changes in his condition (Cherry, 1999; Fillet et al., 1999a, 1999b; Challis et al., 2002; Oregon Senior and Disabled Services, 2004). Several experimental programs have been implemented in the

United States, in which a care manager took overall responsibility for elderly with dementia and their families. Studies that monitored these programs found that their outcomes were positive, including that they alleviated the burden on family members, improved the use of formal services, and ensured that services were adapted to the needs and condition of the elderly person and his family. These programs were also found to delay or prevent institutionalization and improve coordination among health and social services (Challis et al., 2002; Cox and Albus, 2001; Miller, 1999; Yordi et al., 1997). In light of these outcomes, consideration should be given to training professionals in Israel to be "dementia" care managers.

### **Gaps among Regions**

The study found differences in the services available to the elderly in Jerusalem and in Kiryat Gat, as well as differences in the unmet needs of the family caregivers of the elderly in the two cities. It is thus important to develop a comprehensive policy covering health and social services for elderly with dementia, as well as to establish guidelines for detection, diagnosis and treatment of dementia.

The findings of this study have already provided an important base of information for decisionmaking and policy-setting regarding elderly with dementia. They are currently providing the basis for the development of an experimental intervention program, to be implemented jointly by Clalit Health Services, ESHEL, and other organizations. During the past year, the findings were presented to representatives of the Ministry of Health, Ministry of Social Affairs, the health plans and the National Insurance Institute. For example, the findings were presented to top-level staff of the Geriatrics Division of the Ministry of Health, and members of Israel's National Geriatrics Council. The findings were also presented to the management of the Alzheimer's Association of Israel and to researchers from abroad.

This study was initiated and implemented jointly by researchers from the Myers-JDC-Brookdale Institute and physicians from the neuro-psychogeriatric department of Herzog Hospital in Jerusalem.

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