



RESEARCH REPORT

Quality of Care for Dementia Patients, their Unmet Needs and those of their Families

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The study was funded by the Israel National Institute for Health Policy Research

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Executive Summary

1. Introduction

Dementia in all its forms, including Alzheimer's, is a chronic degenerative disease. There is currently no cure for it and dementia patients can expect to end their lives after years of physical, mental and emotional suffering.

A 2002 national survey – the only one conducted in Israel – found that approximately 16% of older adults living in the community were suffering from dementia – 7% with mild dementia, 4% with moderate dementia and 5% with severe advanced dementia.¹ Studies in Israel and abroad have shown that dementia patients have multiple unmet needs, as do members of their families, who bear the brunt of the care burden. That is why dementia presents a considerable challenge to the health and social service systems, which are required to adopt a coordinated system-wide approach (WHO, 2012) in order to ensure high quality holistic care (World Alzheimer Report, 2013).

The current study was intended to provide an up-to-date comprehensive picture of the quality of care of dementia patients living in the community in Israel and of their families, a decade after the previous study, in light of developments in Israel in recent years, particularly activities currently conducted through the Ministry of Health National Dementia Program. The study findings will form the basis for further action to implement this national program and outline suitable programmatic directions for developing and improving services.

2. Study Goals

1. To describe the existing services for dementia patients living in the community and the quality of medical, nursing and social care provided to them; and to describe their unmet needs and the extent of activity to plan early treatment.
2. To examine the burden on the family caregivers and their satisfaction with the health and social services and to identify their unmet needs.

3. Study Design

The study population included a random sample of members of the Maccabi Healthcare Services and Leumit Health Services health plans, whose computerized medical records included a diagnosis of dementia (IDC-10: F00, F01, F03). In the sampling process, which included obtaining consent from the family physician and a family member for the interview, we obtained the names of 407 family members of dementia patients, and interviewed 321 of them by telephone (79%). The interview was conducted using a closed structured questionnaire, which included Functional Assessment staging (FAST), a validated and reliable measure that examines the patient's level of functioning on a scale of 1 (normal) to 7 (severe advanced dementia).

¹ Wertman, E., Brodsky, J., King, Y., Bentur, N., & Chekhir, S. 2007. "An Estimate of the Prevalence of Dementia among Community-Dwelling Elderly in Israel." *Geriatr Cogn Disord* 24: 294-299.

4. Findings

4.1 Quality of Care of Dementia Patients in the Community

- ◆ 59% of the dementia patients were women; the average age was 82, ranging from 56-105; 9% of the patients lived alone; 20% lived with a caregiver (round-the-clock) and the remainder (71%) lived with a family member. Forty percent had mild-to-moderate dementia (levels 2-5) and 60% had advanced dementia (levels 6-7), with a higher percentage among those aged 85+. Sixty-three percent suffered from pain and the percentage was higher among those with advanced dementia.
- ◆ 92% had been at least once or regularly to a neurologist, geriatrician or psychiatrist; 36% were in a health plan home care unit – 48% of those with advanced dementia and 18% of those with mild-to-moderate dementia.
- ◆ 37% had been hospitalized in a general hospital in the previous year – 42% of patients with advanced dementia, 29% of those with mild-to-moderate dementia, almost double the rate of all persons age 65+. Twenty-seven percent of the dementia patients had gone to the emergency room without being hospitalized.
- ◆ The dementia patients were taking an average of 6 medications every day (excluding vitamins and food supplements).
- ◆ 45% were taking medication for memory loss, regardless of the level of dementia. Forty percent of the family members believed that the medication was helping, 29% did not know, and 31% did not believe it was helping, regardless of the level of dementia. Thirty-two percent of the family members of dementia patients not receiving medication for memory loss believed that they should be taking it.
- ◆ 40% were taking tranquilizers – 44% of the patients with advanced dementia, 33% of those with mild-to-moderate dementia. Seventy-four percent of the family members believed that the medication was helping the patients and 8% of the family members of dementia patients not taking tranquilizers believed that they needed them.
- ◆ 31% of the dementia patients were taking antidepressants, regardless of the level of dementia – 46% of those living alone or with a caregiver only vs. 26% of those living with other family members. Sixty-six percent of the family members believed the medication was helping, 18% did not know, and 16% did not believe that it was helping, regardless of the level of dementia. Sixteen percent of the family members of patients who were not receiving medication thought that they needed it.
- ◆ 41% of the family members reported that communication among the care providers was good or very good, 8% did not think it was very good or was not at all good, and 51% reported that there was no coordination at all among the care providers. The percentage was lower among relatives of patients in home care units (47%) than those who were not (65%).
- ◆ According to 57% of the family members, someone at the health plan was responsible for coordinating all the care for the dementia patient, in most cases the family physician.

- ◆ 70% of the family members reported that a physician had told them that the patient had dementia. The average time that they had known about the illness was 3.8 years.
- ◆ 51% of the family members reported that the family physician had explained to them about memory loss and answered their questions, but 49% reported that he had not discussed the matter with them. Only 10%-30% had been given guidance about subjects such as safety and the stages of the illness. Thirty-six percent would have liked more explanations about memory loss and about the illness.
- ◆ Only 16% of family members reported that they had spoken with the patients about a treatment plan should the patients become unable to express their wishes; and only 10% said that a physician had spoken about it with the patient.
- ◆ According to 47% of the family members, the dementia patients had given them power of attorney, but they did not know whether this referred to property or personal care. Forty percent of the patients had a legal guardian.
- ◆ Forty-one percent of the patients had a caregiver provided by the National Insurance Institute for several hours per week and a further 36% had 24-hour care. In addition, 63% were in the care of a social worker, but only 14% attended daycare centers and 13% social clubs. About half of the family members would have liked the patient to go out more often to a daycare center or club and about half of the family members of those who did not go at all would have liked them to do so. Only 7% of the patients had a volunteer visitor and about half of them expressed interest in having one.

4.2 Burden on the Caregivers

- ◆ 66% of the family caregivers were women; the average age was 58. Thirty percent of the caregivers were the spouses of the dementia patients and the remainder were offspring. The financial status of 82% was good or very good, and of the remainder, not very good or not at all good. Thirty-six percent of the family members had a physical disability or health problem.
- ◆ The family members paid caregivers an average of NIS 4,730 per month; 25% purchased medication privately, and 28% went to private physicians. In addition, 64% of the family members who were working reported that they had had to take time off work in order to care for their relative.
- ◆ 47% of the family members reported feeling down, depressed or hopeless in the previous month. Twenty-eight percent had considered transferring the patient to a nursing home.
- ◆ 66% of the family caregivers said that the care burden was heavy or very heavy – 73% of those caring for patients with severe dementia and 54% of those caring for patients with mild-to-moderate dementia.
- ◆ A logistic regression multivariate analysis found that a heavy burden was independently associated with characteristics of the patient – advanced dementia, a "younger" age and multiple chronic illnesses – and of the family caregiver – health problems and poor financial status.

5. Conclusions and Recommendations

- ◆ As shown by the characteristics of the patients, dementia patients have multiple needs, due to the fact that dementia tends to appear late in life, along with additional chronic illnesses and pain, making patients dependent on those around them.
- ◆ Most older adults with dementia had been treated at some stage by a specialist (e.g., geriatrician or neurologist), but the percentage of families in the care of social workers and the percentage of advanced dementia patients entitled to home care units should be increased.
- ◆ Communication and cooperation among the various care providers must be improved, either by referring the patients to home care units or by appointing a care coordinator.
- ◆ Although most of the family members reported that the primary care physician was aware of the patients' memory problems, only half of them had been given explanations by the physician about dementia and only a few had been given guidance about various aspects of caring for dementia patients. It is necessary to raise the awareness of primary care physicians about the importance of communication with family caregivers and the need to give them guidance about dementia.
- ◆ Physicians and family members should be made more aware of the importance of the advance planning tools (discussion about care preferences, advance directive document and power of attorney) and should be given the necessary tools to conduct future treatment planning.
- ◆ It would be a good idea to develop welfare services at the clubs or daycare centers that are adapted to the health status and needs of the dementia patients.
- ◆ When discussing family caregivers of elderly dementia patients, it is important to identify those who themselves have a medical disability, who do not have spouses, and whose financial status is not good, as well as those caring for a relatively young patient with other chronic illnesses. They should be recognized as a group at risk of having a heavy or very heavy care burden, and given whatever support is necessary. In addition, the data show that the likelihood of a family caregiver experiencing a heavy burden can be reduced by providing better care of the elderly relative. This, through good communication among the care providers, by the family physician recognizing the patient's memory problems, and by providing a diagnosis and explanations to the family members about dementia.

Since a Ministry of Health committee is currently engaged in implementing the National Program for Addressing Alzheimer's Disease and Other Types of Dementia, and the health plans are developing programs to treat dementia patients in the community, the findings of this study will help to identify unmet needs and develop appropriate services for them.

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