



Dealing with Early Onset Dementia: The perspective of family caregivers and professionals

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Abstract

Background

The rate of individuals with early-onset dementia (under the age of 65) in Israel is less than 2% of all patients with this disease. Like other illnesses, the burden of care for these patients falls mainly on family members. However, the younger age of the patients and the progressive nature of the disease present unique challenges for family caregivers. In Israel, there are few resources available for individuals diagnosed with early-onset dementia (hereafter, young patients) and their family caregivers.

Objectives

1. To describe the challenges and difficulties faced by family members who care for young patients.
2. To review existing services and the services lacking for young patients and their families.
3. To outline possible ways of improving the quality of life for young patients and their families.

Methodology

The study combined diverse research methods and was based on three sources of information: (1) semi-structured in-depth interviews with five family members caring for young patients insured by Maccabi Healthcare Services; (2) semi-structured in-depth interviews with nine professionals specializing in early-onset dementia; (3) a telephone survey of 17 family members caring for young patients insured by Maccabi Healthcare Services.

Main Findings

Young patients and their family caregivers face unique issues and needs. The disease impacts all aspects of the young patients' lives, their immediate family members, and even broader circles. Due to the rarity of the disease, the diagnostic process for young patients takes significantly longer than for older ones. During and after the diagnostic process, young patients and their families face a situation of uncertainty. As a result of the disease, young patients are forced to leave their jobs, even though they are still of working age. The family unit, which often includes young children, undergoes a shift in roles. Social life becomes limited, leading to feelings of loneliness and isolation for both the young patients and their families.

Despite the broad impact of the disease, existing services for this population are limited and only partially address their needs. In interviews with experts in the field, possible solutions were identified for developing additional resources and services of various kinds to improve the quality of life for these young patients and their families.

Recommendations

This study identified a lack of services and frameworks that could significantly improve the lives of young patients and their families. Consequently, the study includes recommendations to expand services in four main areas: (a) the health-medical sphere; (b) the economic-employment sphere; (c) the social-emotional sphere; and (d) the governmental-legislative sphere. The main recommendations are as follows:

- Increase awareness of the disease among physicians, particularly family physicians and neurologists.
- Make services such as physiotherapy, occupational therapy, and dietary consultations accessible to young patients and tailor them to their specific needs and the disease's progression.
- Maintain routines adapted to the early stages of the disease, during which young individuals can still function and interact with their surroundings.
- Assist young patients and their families in fully exercising their rights.
- Provide emotional support to young patients and their families at all stages of the disease to help them cope with the challenges posed by the illness.
- Establish daily recreational programs tailored to young patients and adapted to the various stages of the disease.
- Create a special status for young patients and their families and promote legislation advancing the concept of "young dementia patients" to facilitate their interactions with government offices and agencies.
- Grant family caregivers workplace rights, economic benefits, or financial relief, and assist them in claiming their entitlements and allowances.
- Change societal discourse and attitudes toward individuals with dementia in general and toward young people with dementia in particular.

Some of these recommendations are complex in nature and require significant preparation or changes to implement them, suggesting a medium-to-long-term timeline for execution. However, some of the recommendations can be implemented in the short term, requiring only minor adjustments or changes.

It is worth noting that in 2024, leading organizations in the field of dementia¹ approached the Ministry of Welfare and Social Affairs with a request to amend regulations for welfare services for people with disabilities and include early-onset dementia under the Equal Rights for Persons with Disabilities Law. While the proposed amendment partially addresses the recommendations presented in this report, at the time of writing the proposal had not yet been approved. Consequently, young patients with dementia are not recognized by the relevant frameworks for young patients in general nor by those for elderly dementia patients.

¹ Ezer Mizion, Emda, Melabev and Y.O.D. Israel ("A Home for Young People with Dementia").