Medicosocial care for persons suffering from Alzheimer’s disease and related disorders

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Key words: the elderly, dementia, services.

Summary. Lithuania, like many European countries, is facing the problem of ageing population. The ageing society is accompanied by an increase in the prevalence of the disorders that are characteristic for old age. This article presents an overview of the current situation with respect to care of patients with dementia in Lithuania. Calculations based on epidemiological studies in other countries reveal that at least 31 000 persons may be suffering from dementia in Lithuania, with 6407 new cases occurring each year. Management of persons with dementia is mainly conducted by psychiatrists and neurologists with a few geriatricians. Mental health centers with interdisciplinary teams assure medical treatment, primary diagnosis of dementia, family consultations, managing of social and psychological problems and visits to homes when needed. Institutional services and home help services for persons with dementia are scarce and underdeveloped. Our future priorities in developing care for people with dementia are to improve the timely diagnosis and comprehensive management of dementia with the establishment of a continuity of high quality social services with special emphasis on home help and the support of family members.

Introduction
Lithuania, like many European countries, is facing the problem of an ageing population. The increase in the number of elderly people during the last century has been continuous. At the beginning of 2002 Lithuania counted over 494 000 elderly people (65 years and older), who made up 14.2% of the total population (3.5 millions) (1). People older than 75 years make up 5.2% of the total population (1).

According to the population projections until 2020 published by the Department of Statistics (2), the number of older people will increase, and the population will age quickly in spite of population growth (Fig.). This demographic process affects the prevalence of diseases that are typical of the elderly. Cognitive impairment and dementia are the principal problems in the care of the elderly (3), and they make high demands on health and social care provision.

The objective of this article is to present an overview of the current situation with respect to care of persons with dementia in Lithuania.

Material and methods
Literature search of Lithuanian publications was performed in order to identify the data on epidemiology and management of dementia. The annual publications on demography and health and social care provision from the Department of Statistics covering years 1999–2003 were studied. The database of the Ministry of Social Care and Labor was searched for data on institutional care and had been searched. The National Mental Health Centre had been contacted in written form in order to gather the data on prevalence and incidence of dementia and numbers of psycho-geriatric beds in the country.

Results
Available data on prevalence and incidence of dementia in Lithuania
The prevalence of dementia increases with age. Precise statistical data on persons suffering from dementia in Lithuania does not exist, since there are no epidemiological studies or a register for the disorder. The data from the Lithuanian National Mental Health Centre of Lithuania are obtained only from mental health care centers, and so the cases diagnosed by neurologists are not included in that database. The National Mental Health Centre database (4) indicates that the total number of dementia cases in 2002 was 14823, out of which Alzheimer’s disease accounted for 495, vascular dementia – for 2161, and other dementias – for 12167. The incidence of new cases of dementia in 2002 was 1524: Alzheimer’s – 124, vascular dementia – 456, and other dementia – 954. There was an increase in dementia cases compared with the year 2000, when there were a total of 5337 cases of dementia (4). Based on data from other countries, approximately 5% of persons aged 65 years and over...
may suffer from dementia with two-thirds of them having Alzheimer’s disease (5). More precise data are given in a study of Rotterdam (6, 7), based on which we calculated the expected prevalence and incidence of dementia in 2002. Using the figures from Rotterdam study, roughly estimated prevalence would be 31000 persons and yearly incidence more than 6000 in Lithuanian population.

The projections for the future show an increase in the number of patients with dementia. According to the projections published by the Department of Statistics of Lithuania the average population in 2020 will consist of 3.7 million people, and those older than 65 years will make up 15.3% of the total population (2).

With increasing numbers of elderly persons and increasing life expectancy, mental health requires more attention, as well as the implementation of adequate standards of care.

**The management of dementia in Lithuania**

Dementia tends to be diagnosed late and with low accuracy. When diagnosis is belated, opportunities for the support of the patients and their carers are limited (8).

The diagnosis and assessment of persons with dementia are performed by the specialists (neurologists, psychiatrists, rarely by geriatricians) in the “secondary” or “tertiary” services from referrals by general practitioners or other specialists. Algorithms and guidelines for making diagnoses are not established at the moment in Lithuania, therefore internationally published guidelines (9–19) are used in practice. According to the order issued by the Minister of Health, Alzheimer’s disease can be diagnosed by psychiatrists and neurologists (20). When the diagnosis and cause of dementia are both confirmed, specific treatment and prevention from certain risk factors are available. There is a great need to diagnose dementia early, since the newest and specific treatment strategies are available in Lithuania; donepezil, memantine, galantamine, rivastigmine are registered for the treatment of Alzheimer’s disease, though, since the last two of these are not reimbursable, they are not used in practice. Management of persons with dementia is mainly conducted by psychiatrists, neurologists, and few geriatricians.

On the primary health care level psychogeriatric care is conducted by a team of specialists (a psychiatrist, a mental health nurse, a social worker, and a psychologist) in the mental health centers (in total there are 62 centers in the country, including 14 with legal responsibilities). These centers ensure medical treatment, primary diagnosis of dementia, family consultations, managing of social and psychological problems and visits to homes when needed. The assessment of health and social needs is performed, but it cannot result in comprehensive care plans and action for the demented persons with functional limitations because of the lack of services and institutions. Nursing and long-term care issues are tackled together with general practitioners. In rural areas persons with dementia mainly are cared for by general practitioners and community nurses.

**Institutional services.** Short-term care (maximum length of stay of four months) is provided by the Nursing Hospitals, but they lack dementia-specific units. There are four psychogeriatric departments with 115 beds in total in the country managing elderly patients.
with psychiatric disorders and demented persons with exacerbated emotional and behavioral problems. If there is no access to specialized psychogeriatric care, demented persons are admitted to acute psychiatric units. Those who live alone and need permanent social and medical care are accommodated in State care institutions for the elderly and care institutions for mentally disabled adults, which are populated with all age groups. There were 22 long-care institutions for mentally disabled adults with 5288 residents in the country on July 1, 2003 (21). Table 1 illustrates the institutions for mentally disabled adults and the number of residents in 2003. As we can see from this table, people older than 60 years make up 37.9% of the total number of residents in care institutions for the mentally disabled. Persons with dementia make up 19% of the older population in these institutions. Unfortunately, there is no data on the type of units where these persons live.

The state care institutions for the elderly are not populated only by elderly residents, as shown in Table 2. People with dementia make up 14% of all residents in State care institutions for the elderly.

Very few long-term care institutions are designed for the needs of persons with dementia (100 beds in Vilnius county).

Summarizing the numbers of people with dementia accommodated in long-term care institutions (Tables 1 and 2) who make up 2% of all the projected numbers of persons with dementia (Table 1) we conclude that people with dementia are mainly cared for at home by their relatives.

Home-based services are very limited for the elderly and can be received only if they are single, without any relatives, and can partially pay for the services. Those who need home help may address local social service departments run by the municipalities. Based on social and medical criteria the elderly are accepted for home help programs. Home help provided by social workers and workers providing care through visits was received by 4237 elderly persons in 2001 (22). There is no data on the prevalence of dementia among the users of social services, but only persons with mild dementia are eligible for home help.

There are five self-support groups of carers whose family members suffer from dementia in the country, but they lack formal support, information, and education on dementia. A study on carers of persons with dementia revealed a lower quality of life, especially of spouses caring for demented persons (23, 24). The Lithuanian Alzheimer Association, consolidating the carers, was set-up on February 16, 2003.

### Discussion

Dementia is a massive problem in Lithuania. It is underestimated, underdiagnosed, and undermanaged. Lithuanian periodicals for the specialists publish the articles on dementia, but mainly they are review articles. The first doctoral thesis based on clinical cases of Alzheimer disorder and vascular dementia was published by G. Kaubrys in 2000 (25). Few master theses with an emphasis on carers and their quality of life had been conducted (23, 24). There is lack of papers researching prevalence of dementia, nature of dementia, efficacy of treatment and care, and the situation in long-term care institutions.

The theoretically estimated data, which are based on clinical cases, are different from those we have

### Table 1. Residents in care institutions for mentally disabled adults (July 1, 2003)

<table>
<thead>
<tr>
<th>County</th>
<th>Number of institutions</th>
<th>Number of residents</th>
<th>With dementia and Alzheimer’s disease</th>
<th>Age groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>under 60 years</td>
<td>above 60 years</td>
</tr>
<tr>
<td>Kaunas</td>
<td>2</td>
<td>386</td>
<td>7</td>
<td>270</td>
</tr>
<tr>
<td>Klaipėda</td>
<td>1</td>
<td>556</td>
<td>59</td>
<td>336</td>
</tr>
<tr>
<td>Marijampolė</td>
<td>4</td>
<td>676</td>
<td>28</td>
<td>377</td>
</tr>
<tr>
<td>Panevėžys</td>
<td>4</td>
<td>745</td>
<td>77</td>
<td>451</td>
</tr>
<tr>
<td>Šiauliai</td>
<td>3</td>
<td>1 030</td>
<td>74</td>
<td>640</td>
</tr>
<tr>
<td>Tauragė</td>
<td>1</td>
<td>201</td>
<td>29</td>
<td>127</td>
</tr>
<tr>
<td>Telšiai</td>
<td>2</td>
<td>473</td>
<td>17</td>
<td>309</td>
</tr>
<tr>
<td>Utena</td>
<td>2</td>
<td>521</td>
<td>2</td>
<td>322</td>
</tr>
<tr>
<td>Vilnius</td>
<td>3</td>
<td>700</td>
<td>88</td>
<td>443</td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
<td>5 288</td>
<td>381</td>
<td>3 285</td>
</tr>
</tbody>
</table>

*Data source:* Department of Audit and Supervision of Social Establishments at the Ministry of Social Security and Labor, Report on the first half-year of 2003.

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from the National Mental Health Centre. The nature of dementia and proportions of different causes of dementia in Lithuania comparing with the other countries are different. Other epidemiological studies (7, 26) indicate that majority of dementia cases account to Alzheimer’s disorder, whereas in Lithuania comparatively small proportion is attributed to Alzheimer’s disorder. This discrepancy could be explained by the lack of obligatory reports of all diagnosed cases and incomplete diagnosing procedure, which is shown by high numbers of unspecified dementia. Epidemiological studies could reveal the proportions on different reasons of dementias, which may disagree with the data from other countries (5, 26, 27). The true prevalence and incidence of dementia and other age-related disorders are unknown. Since life expectancy, prevalence of the disorders, and living conditions are different in different countries, the data based on calculations from Rotterdam study are insecure. To estimate real prevalence and incidence we need epidemiological studies on dementia and other age-related disorders. There are no data on degree of dementia in our country, which could be helpful in planning health and social care services, although the degree of dementia alone is not a good indicator of the need for institutional care (28).

Dependency level could predict needs for services. The calculations according to Scottish model (28) indicate that 6% of persons with dementia would be independent, 11% needed care once a week, 48% needed care at regular intervals during the day for dressing, meals, etc., and 34% needed constant care and supervision.

Regardless how many persons with various degrees of dementia are in Lithuania the numbers of institutions and services are too low. There are several reasons for that. One reason is that we do not have a national register for dementia, thus some cases are not reported and not known to the statisticians. Another probable cause is low awareness of staff working with the elderly of dementia in the elderly. The numbers of dementia cases are increasing, and this means higher awareness of the specialists of dementia and more registered cases. Efforts should be made to establish Memory Clinics, which demonstrate high efficiency (29), for drug treatment and for intervention to help the family carers and prevent family breakdowns.

With the development of geriatric medicine in Lithuania the numbers of geriatricians and geriatric departments will increase, which will contribute to more timely screening and management for those with the dementia syndrome. The introduction of old age psychiatry or psychogeriatric speciality in the country would foster mental health care in the elderly and the better management of dementia.

Social services for people with dementia are underdeveloped and do not meet criteria based on integrity and continuity. “When family members act as carers, this should be expressly recognized by giving them certain legislatively based rights, and their own needs, e.g. access to information, training, respite and other support services, should be fully met” (30).

Public care facilities should be established, such as day-centers, home care, respite care and the use of assisting devices, including modern enabling technologies (31–34), as they are more effective than would be possible in a generic service.

A literature survey indicates high numbers of elderly persons with dementia in nursing homes. The study of nursing homes in Norway by K. Engedal and P.K. Haugen revealed a 74% prevalence of the dementia syndrome among the residents (35). Our data on State care institutions for the elderly gives a pic-
ture of a low prevalence of dementia in these institutions (Table 2). This reveals a low awareness of dementia and lack of studies.

The lack of data regarding living arrangements and unit types suggests that there is a lack of dementia-specific units in long-term care institutions. The data from Tables 1 and 2 suggest insufficient quality of care for demented persons, because they are not diagnosed for dementia in the care homes and those who stay in the institutions need care in small groups and a personalized environment according to their needs and diagnosis. The studies on long-term care (36–38) suggest that people with dementia function better in small, domestic style units cared for staff with dementia training. Referring to the recommendations by the European Committee for Social Cohesion (30), “people with dementia should receive dementia-specific services in appropriately designed environments from people who are trained to deliver such care”.

Services need to be organized and delivered in a manner which is sensitive to the individual needs, characteristics of the illness and impact of the disease on the patient and family (28). Planing the services for demented people in Lithuania the first evaluation of the needs should be performed, as extrapolation of the data from other countries might be inaccurate due to cultural differences and dissimilar health and social care systems in the countries. The theoretical model from Scotland (28) suggests that 39.3% of all persons with dementia would need institutional care. The proportions of persons in different settings could be following: 20% in psychogeriatric wards, 31% in nursing homes, 37% in residential homes, and 12% in other long stay. This model is supported by Norwegian study (35), which revealed that about 40% of all demented persons in Norway were cared for in institutions.

Our future priorities in developing care for people with dementia would be: 1) to improve the timely diagnosis and comprehensive management of dementia; 2) to establish continuity of high quality social services with special emphasis on home help; 3) to support family members; 4) to educate staff working with persons with dementia; and 5) to raise awareness of society towards dementia. Imperative for researchers is to conduct epidemiological studies to get real picture on dementia and to evaluate the needs of persons with dementia and their families for community care, medical and social services for physical, spiritual and psychological support.

Conclusions
Currently available data on dementia in Lithuania are incomplete and do not reflect real situation. Inaccurate data do not allow predicting the needs for the services. There is a need for the epidemiological studies and clinical studies on dementia and other age-related disorders.

The management of dementia lacks continuity due to scarcity of full range of services. The expansion of planned dementia-specific services and institutions would enhance better quality of the care for people with dementia and their carers as well.

**Žmonių, sergančių Alzheimerio liga ir su jų susijusiais sutrikimais, medicininė ir socialinė priežiūra**

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**Raktažodžiai:** senyvi žmonės, demencija, paslaugos.

**Santrauka.** Lietuvoje kaip ir daugelyje Europos šalių yra aktuali visuomenės senėjimo problema. Visuomenės senėjimas, socialinės struktūros kaitos pranašumai, geriausiai aiškina dėl dėsnio, kad šalyje yra daugiau žmonių, kuriems būtų reikëti geriausiai įgyvendinti gyvenimo konceptai. Taigi, kad Lietuvoje yra daugiau sergančių Alzheimerio liga ir dėl to poveikis socialinėms struktūroms yra didesnis. Tai reiškia, kad dabartinës geriausios priemones, kurias taikome dėl Alzheimerio ligos, įprastai nesutampa su šiuolaikine pasaulio gyvenimo kultūra. Taigi, kad dabartinës geriausios priemones, kurias taikome dėl Alzheimerio ligos, įprastai nesutampa su šiuolaikine pasaulio gyvenimo kultūra.
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