

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

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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 psychogeriatric 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

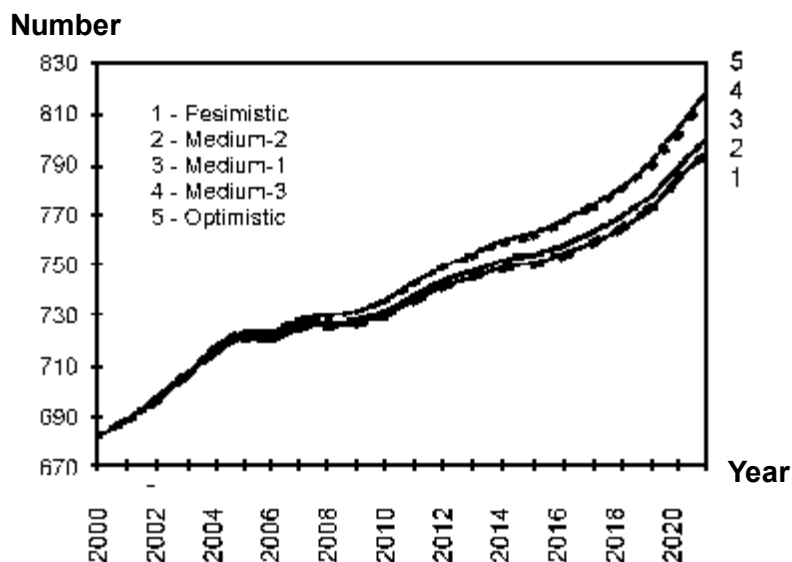


Fig. Trends in population aged 60 years and over, 2000–2021

Data source: Population Projections of Lithuania 2000–2002. Vilnius: Lithuanian Institute of Philosophy and Sociology, Department of Statistics of the Government of the Republic of Lithuania; 1998.

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, with-

out 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)

County	Number of institutions	Number of residents	With dementia and Alzheimer' disease	Age groups	
				under 60 years	above 60 years
Kaunas	2	386	7	270	116
Klaipėda	1	556	59	336	220
Marijampolė	4	676	28	377	299
Panevėžys	4	745	77	451	294
Šiauliai	3	1 030	74	640	390
Tauragė	1	201	29	127	74
Telšiai	2	473	17	309	164
Utena	2	521	2	322	189
Vilnius	3	700	88	443	257
Total	22	5 288	381	3 285	2 003

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.

Table 2. Residents in State care institutions for the elderly (July 1, 2003)

County	Number of institutions	Number of residents	With dementia and Alzheimer disease	Age groups	
				under 60 years	over 60 years
Kaunas	2	419	134	77	342
Klaipėda	2	468	63	115	353
Alytus	1	128	1	6	122
Utena	2	519	54	167	352
Vilnius	1	247	–	39	208
Total	8	1 781	252	404	1 377

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.

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). Planning 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 rise 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 ja 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 senėjimą sąlygoja ir ligos, kuriomis dažniausiai serga vyresnio amžiaus žmonės. Šiame straipsnyje apžvelgiamas sergančiųjų demencija gydymas ir medicininė bei socialinė pagalba Lietuvoje. Remiantis kitose šalyse atliktais epidemiologiniais tyrimais, manoma, kad dabar Lietuvoje yra 31 tūkstantis sergančiųjų demencija, be to, per metus užregistruojama per 6000 tūkstančius naujų atvejų. Demenciją diagnozuoja ir sergančiuosius šia liga gydo psichiatrai, neurologai bei geriatrai. Psichikos sveikatos centrai su interdisciplinine komanda užtikrina palaikomąjį gydymą, pirminę demencijų diagnostiką, šeimos konsultavimą, socialinių ir psichologinių problemų sprendimą, o prireikus pacientų lankymą namuose. Trūksta institucinių paslaugų bei pagalbos namuose. Pagalbos sergantiesiems demencija sistemos sukūrimo tikslai yra šie: savalaikė diagnostika ir visavertė pagalba gydant ir prižiūrint pacientus, sergančius demencija, bei aukštos kokybės specializuotų socialinių paslaugų sistemos kūrimas ypatingą dėmesį skiriant pagalbai namuose bei šeimos paramai.

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References

1. Demographic Yearbook 2001. Vilnius: Department of Statistics of the Government of the Republic of Lithuania; 2002. p.12.
2. Population Projections of Lithuania 2000–2020. Vilnius: Lithuanian Institute of Philosophy and Sociology, Department of Statistics of the Government of the Republic of Lithuania; 1998.
3. Pathy J, editor. Principles and Practice of Geriatric Medicine. 3rd ed. Toronto: John Wiley & Sons; 1998.
4. The Database of the National Mental Health Centre, Vilnius, Lithuania. Available from: URL: <http://www.std.lt>
5. Ott A, Breteler MM, van Harskamp F, Claus JJ, van der Cammen TJM, Grobbee DE, Hofman A. Prevalence of Alzheimer's disease and vascular dementia: association with education. The Rotterdam Study. *BMJ* 1995;310:979-83.
6. Breteler MM, Ott A, Hofman A. The New Epidemic: frequency of dementia in Rotterdam Study. *Haemostasis* 1998;(3-4):117-23.
7. Ott A, Breteler MM, van Harskamp F, Stijnen T, Hofman A. Incidence and risk of dementia. The Rotterdam Study. *Am J Epidemiol* 1998;147(6):574-80.
8. Lovestone S, Gauthier S. Management of dementia. London: Martin Dunitz Ltd; 2001.
9. Lopez OL, Larumbe MR, Becker JT, et al. Reliability of NINDS-Airen clinical criteria for the diagnosis of vascular dementia. *Neurology* 1994;44:1240-5.
10. Small GW, Rabins PVB, Buckholtz PP, DeKosky NS, Ferris ST, Finkel SH, et al. Diagnosis and treatment of Alzheimer's disease and related disorders: consensus statement of the American Association for Geriatric Psychiatry, The Alzheimer's Association, and the American Geriatric Society. *JAMA* 1997;278(16):1363-71.
11. Practice parameter for diagnosis and evaluation of dementia (summary statement). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology* 1994;44:2203-6.
12. McKhann G, Drachman D, Folstein M, et al. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspice of the Department of Health and Human Services Task Force on Alzheimer's Disease. *Neurology* 1984;34:939-44.
13. McKeith IG, Kosaka K, Perry EK, Dickson DW, Hansen LA, et al. Consensus guidelines for the clinical and pathological diagnosis of dementia with Lewy bodies (DLB): report of the consortium on DLB international workshop. *Neurology* 1996;47:1113-24.
14. Neary D, Snowden JS, Gustafson L, et al. Frontotemporal lobar degeneration: a consensus on clinical diagnostic criteria. *Neurology* 1998;51:1546-54.
15. The ICD-10 Classification of Mental and Behavioral Disorders. Clinical Description and Diagnostic Guidelines. Geneva: WHO; 1992.
16. Oslin D, Atkinson RM, Smith DM, Henrie H. Alcohol related dementia: proposed clinical criteria. *Int J Geriatr Psychiatry* 1998;13:203-12.
17. Kretschmar HA, Ironside JW, DeArmond SJ, Tateishi J. Diagnostic Criteria for Sporadic Creutzfeldt-Jacob Disease. *Arch Neurol* 1996;53(9):913-20.
18. Petersen RC, Stevens JC, Ganguli M, Tangalos EG, Cummings JL, DeKosky ST. Practice parameter: Early detection of dementia: Mild cognitive impairment (an evidence-based review) Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology* 2001;56(9):1133-42.
19. Resiberg B, Burns A, Brodaty H, Eastwood R, Rossor M, Sartorius N, Winblad B. Diagnosis of Alzheimer's Disease. Report of an International Psychogeriatric Association Special Meeting Work Group Under the Cosponsorship of Alzheimer's Disease International, the European Federation of Neurological Societies, the World Health Organization, and the World Psychiatric Association. *Int Psychogeriatrics* 1997;9 Suppl 1:11-38.
20. Lietuvos Respublikos Sveikatos apsaugos Ministro įsakymas „Dėl Alzheimerio ligos diagnozavimo ir gydymo metodų bei Alzheimerio ligos diagnostinių kriterijų patvirtinimo.“ (A Decree of Health Security Minister of the Republic of Lithuania “Concerning diagnostics and methods of treatment of Alzheimer's disease and the ratification of the diagnostic criterias for Alzheimer's diseases.) *Valstybės žinios* 2000;57:56.
21. 2003 m. Pirmojo pusmečio ataskaita. Socialinių įstaigų priežiūros ir audito departamentas prie Socialinės apsaugos ir darbo ministerijos. (Department of Audit and Supervision of Social Establishments at the Ministry of Social Security and Labour.) Available from: URL: <http://tc.sipad.lt>
22. Health and Social Care. Vilnius: Department of Statistics by Lithuanian Republic Government; 2001.
23. Skauronaite A. Demencija sergantis asmuo namuose: slaugytojo gyvenimo ypatumai. (Persons with dementia at home: peculiarities in carer's life.) Master thesis. Kaunas: Vytautas Magnus University; 2002.
24. Urbonienė I. Namuose slaugančiųjų demencija sergančiuosius gyvenimo kokybė. (Quality of life of carers of persons with dementia at home.) Master thesis. Kaunas University of Medicine; 2003.
25. Kaubrys G. Alzheimerio ligos ir kraujagyslinės demencijos klinikinių ypatumų priklausomybė nuo apolipoproteino E genotipo ir aterosklerozės išreikštumo. (The dependence of clinical peculiarities in Alzheimer disorder and vascular dementia from genotype apoE and signs of atherosclerosis.) PhD thesis. Vilnius University; 2000.
26. Suh GH, Shah A. A review of the epidemiological transition in dementia – cross-national comparisons of the indices related to Alzheimer's disease and vascular dementia. *Acta Psychiatr Scand* 2001;104:4-11.
27. Fratiglioni L, Grut M, Forsell Y, Viitanen M, Grafström M, Holmen K, et al. Prevalence of Alzheimer's disease and other dementias in an elderly urban population: relationship with age, sex, and education. *Neurology* 1991;41:1886-92.
28. Alzheimer Scotland. Planning Signposts for Dementia Care Services; 2000.
29. Luce A, McKeith I, Swann A, Daniel S, O'Brien J. How do memory clinics compare with traditional old age psychiatry services? *Int Geriatr Psychiatry* 2001;16:837-45.
30. O'Shea E, Group of Specialists on Improving the Quality of Life of Elderly Dependent Persons. Improving the quality of life of elderly persons in situations of dependency. Council of Europe Publishing; 2002.
31. Bjerneby S, Topo P, Holthe T. Technology, Ethics and Dementia. Norwegian Centre for Dementia Research, INFO-banken; 1999.
32. Nolan M, Grant G. Regular respite: an evaluation of a hospital rota bed scheme for elderly people. Research paper No. 6. London, Age Concern Institute of Gerontology; 1992.
33. Stalker K, editor. Development in Short-Term Care: Breaks and Opportunities. Research Highlights in Social Work. London: Jessica Kingsley; 1996.
34. Brodaty H, Gresham M, Luscombe G. The Prince Henry Hospital Dementia Caregiver's Training Programme. *Int J Geriatr Psychiatry* 1997;12:183-92.
35. Engedal K, Haugen PK. The prevalence of dementia in a sample of elderly Norwegians. *Int Geriatr Psychiatry* 1993;8: 565-70.
36. Marshall M. Small scale, domestic, long-stay accommodation for people with dementia. University of Stirling, Dementia Services Development Centre; 1993.
37. Thomas M. Innistaigh: a domus unit in Stanraer. University of Stirling, Dementia Services Development Centre; 1994.
38. O'Shea E, O'Reilly S. An Action Plan on Dementia, National Council on Ageing and Older People. Report No. 54. 1999.

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