



OECD case study on dementia

SWEDEN

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Förord

Denna rapport innehåller en unik faktasammanställning kring demenssjukdomar i Sverige, uppdaterad fram till september 2002. Materialet har tagits fram till en OECD-rapport, som publicerats sommaren 2004. För att detta material ska bli tillgängligt för svenska läsare publiceras den nu som en rapport hos Stiftelsen Stockholms läns Äldrecentrum. Rapporten är på engelska. Den består av en beskrivande del och i en särskild bilaga en omfattande statistikdel.

Texten är strukturerad efter de frågeställningar OECD önskat få belysta från varje land som deltagit i kunskapssammanställningen.

Stockholm 2004-10-05

Sven Erik Wånell
Chef Stiftelsen Stockholms läns Äldrecentrum

Författarnas förord

Denna rapport har tagits fram som Sveriges bidrag till en jämförande studie kring demens i 9 OECD-länder. Deltagande länder har förutom Sverige varit, USA, Kanada, Australien, Japan, Frankrike, Spanien, Storbritannien och Tyskland. Studien är ett delprojekt i OECD:s Hälsoprojekt och är tänkt att tillsammans med en studie kring "Long-Term Care" ta fram hälsoekonomiska och strukturella jämförelser mellan OESD-länderna när det gäller äldreomsorg och demensvård. Syftet med studien är att öka kunskaperna kring vilka insatser och faktorer som ger god effekt i vård och omsorg om demenssjuka personer och ge olika beslutsfattare underlag för utveckla styrformer och politik inom området. OECD-rapporten publicerades sommaren 2004.

Den svenska rapporten innehåller dels en kvalitativ del med beskrivande svar på frågeställningar som rör hur demensvården är organiserad i Sverige, dels en kvantitativ del med faktaunderlag och siffermaterial. En del av detta material är sammanställt för första gången i denna rapport. Förutom den svenska rapporten finns i denna skrift även en kort sammanfattning av syftet med OECD-studien och de frågeställningar som vi i vår rapport försökt besvara.

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PART A QUALITATIVE INFORMATION

1. Dementia-specific policies, guidelines and planning

1.1 Are there specific policies, strategies, guidelines or regulations for dementia care in your country? If so, please provide details, including the group who developed or has responsibility for them.

There are no official national guidelines for dementia care in Sweden.

However, the main players involved in the treatment of dementia have produced a variety of publications including guidelines for dementia care.

For example:

a. In 1995 Medicinska Forskningsrådet (Medical Research Council) presented a state of the art document offering guidelines for dementia care.

b. The Swedish Council on Technology Assessment in Health Care (*Statens Beredning för Utvärdering av medicinsk teknologi*), which is answerable to the Swedish Ministry of Health and Social Affairs, regularly examines the scientific database for the treatment of different medical conditions from an “evidence-based medical” perspective. One of its current projects concerns dementia; the final report will be available in 2004.

c. The Swedish Medical Products Agency (Läkemedelsverket), which is responsible for the state control of drugs, presents analyses of new drugs and on some occasions broader analyses of different medical conditions. A study in progress at the moment will result in recommendations for dementia care (epidemiology, symptoms, diagnostics, treatment). Previous reports on dementia were published in 1995.

d. Local programs in different parts of Sweden offer guidelines for dementia care; participants in these programs include specialists, representatives of primary health care and municipalities and county councils.

Examples:

Örebro County Council: Dementia study in Örebro county (*Demensutredning i Örebro Län* - in Swedish).

Malmöhus County Council: Care program Conditions of Dementia (*Demensstillstånd* – in Swedish).

Hudiksvall municipality and Primary Care Hälsingland. Dementia care program for municipalities and county councils in Hudiksvall (in Swedish).

e. The Government has recently appointed a national working group consisting of representatives of various authorities and associations and researchers in the field of dementia care. The group's task is to assess the conditions of people with dementia and that of their relatives, and to recommend improvements in dementia care.

f. Ten years ago, some national guidelines for dementia diagnostic criteria as well as advice for diagnostic procedures were published in the official journal of the Swedish Medical Association (*Läkartidningen*: 1-3).

1.2 Do you have an organised program focussed on early detection of dementia and/or Alzheimer Disease? If so, what body is responsible for the program, what does it include, and what is the extent of the program (local, regional, national)?

1.3 Are 'specialist dementia centres' currently used? If so, briefly describe these. Are there information campaigns about these centres?

No national program currently exists for early detection of dementia. The situation varies throughout the country. Certain local programs (county councils, municipalities) regard early detection as an important issue, but the implementation of these programs varies. Some of these programs are listed in section 1.1 d. above

"Memory clinics" linked to some universities integrate clinical work and research. County hospitals (an intermediate form of hospital between the university/region hospitals and the small local hospitals) house special clinics (or parts of clinics) concentrating on specific aspects of dementia care (e.g. diagnostics and drug treatment). Very few local hospitals and even fewer primary health care centres have these types of units. According to *Demensförbundet*, one of the Swedish dementia associations, some 70 units perform dementia diagnostic procedures in Sweden

In some municipalities, special "dementia nurses", are responsible for the care of dementia patients, and are entitled to have other health professionals (such as nurses and home help) working with them, but they are not linked to diagnostic teams. Approximately 20 per cent of Swedish municipalities employ dementia nurses.

Certain specialist clinics, mostly at university-hospital or county-hospital level, have teams of professionals that specialise in dementia care, diagnostic procedures, home visits etc.

Joint projects exist involving dementia researchers and assessment teams. In the following cities (with links to universities) major population-based dementia studies are being conducted: Stockholm, Umeå, Linköping, Malmö, Göteborg, Uppsala and Nordanstig. A new major population-based project (Swedish National project on Aging and Care), funded by the Ministry of Health and Social Affairs, is now under way to establish a national database to be used in elderly care.

Specific campaigns about dementia centres (e.g. memory clinics) are rare but information about them is included in general information and campaigns about dementia. However, in 1994, the National Corporation of Swedish Pharmacies (*Apoteksbolaget*) ran "Dementia Year" – a campaign highlighting different aspects of dementia..

The two Swedish patient/caregiver organisations (*Demensförbundet* and *Alzheimerförbundet*) also run various campaigns about dementia. On World Alzheimer's Day, for example, a wide range of information activities take place both locally and nationally.

1.4 Please describe the policies in your country to develop:

- access to formal care at home for older patients with dementia
- dedicated facilities for dementia care.

1.5 Are there any specific planning processes or financial incentives for the development of specialist centres aimed at managing the early stages of dementia (for example, those staffed by dementia specialists, and focusing on diagnosis at mild stages), or the development of dementia-specific long-

term care facilities? Are there specific planning processes or incentives for the provision of alternative types of facilities for dementia patients, such as small-group homes (for example, 'Cantous').

Formal care for people with dementia living at home

Home help services imply service and personal care in the home provided by the municipality under the Social Services Act. The Social Services Act covers the duty of municipalities to provide social services and care for older people. Under this act, any person who is unable to provide for his or her needs or to obtain provision for them in any other way is entitled to assistance towards their livelihood and towards their living in general. The municipalities are responsible for the casework – which also includes needs assessment – under the Social Services Act. The act further stipulates that municipalities shall endeavour to ensure that older people are enabled to live independently, in secure conditions and with respect shown for their self-determination and privacy. Among other things, the municipality should facilitate for the individual to continue living at home by means of home help services, daytime activities or other such social services. Through support and relief services, municipalities should facilitate the situation for family members caring for older people. The act also requires the municipality to establish special forms of housing accommodation offering service and care for older people in need of special support.

Service tasks include e.g. housework and laundry, help with shopping, post office and bank errands and preparation of meals. Personal care can include assistance with eating and drinking, getting dressed, personal hygiene and moving about. For those in need, municipal security alarms are available, which are usually linked to the nearest special housing, where personnel respond and attend to alarms they receive. The elderly today can receive advanced care in their homes 24 hours a day. Home nursing today can mean both qualified care and highly specialised medical care several times a day, as well as terminal care. About one third of the people that receive home help services also receive home nursing care. In 2000, roughly 9 per cent of people aged 65 and over were entitled to home help services. The corresponding figure for those aged 80 and over was 21 per cent. We have no specific figures for people with dementia.

Daytime activities and respite care are offered as means-tested support, under the Social Services Act and/or the Health and Medical Services Act. The support of daytime activities is given in the form of treatment and daytime rehabilitation for people suffering from dementia, people with mental functional impairment and people otherwise in need of treatment and rehabilitation. Roughly 90 per cent of the municipalities in Sweden have organised dementia-specific day centres.

A special transport service to the day centres is available nationwide. Eligibility for this service varies between municipalities as do other entitlements such as the number, frequency and length of journeys. Taxis generally provide this transport but wheelchairs vehicles are also available when required.

In 1998, roughly 3 per cent of people aged 65 and over were provided with daytime activities at some point. Respite care is given in the form of temporary housing combined with treatment, rehabilitation and care, partly for purposes of relief and alternate care. Respite care is offered in most municipalities in different ways. In most cases, beds in different types of special housing accommodation are used. Since this is part of the municipality's responsibilities,

the care manager (**CM**) is involved in the planning. Different forms of respite care are available. Short-term respite care (normally one or two weeks) is offered if the care provider needs a break for personal or medical reasons. Another type of care is based on a regular shift model, where the dementia patient is at home for three weeks and at a care centre for two weeks, and so on. Another patient may have the opposite schedule (i.e. two weeks at home and three away), which enables the care centre to offer place-sharing. Although these moves may be stressful for the patients, it may be an advantage for the caregivers and may make it possible to postpone institutionalisation. In 1998, roughly 3 per cent of people aged 65 or over received short-term or respite care at some point during the year. The number of patients involved in daytime activities and respite care has improved in recent years but we have no specific or up-to date figures showing how many of people with dementia are receiving this support.

Developments in the 1990s were characterised by the change in responsibility for elderly care. Cuts in resources have led to a reduction in the number of beds for elderly people in county council hospitals. This in turn has increased the pressure on municipal elderly care services and on outpatient services. Elderly people in great need of care have higher priority than older people in less need of care, who to a growing extent have to rely on relatives or volunteers to provide the help and care they need.

There is strong evidence to show that informal carers bear the main responsibility for people with dementia living at home. Based on a number of minor studies, the proportion of informal care vs. formal care could be estimated at about 5–10:1 if the supervision component is also included (the variation depends on methodological issues in this research field). However, figures based on population studies, which will be presented in the second half of 2002, show slightly lower differences between informal and formal care. There is also support for the view that the conditions for informal carers are unsatisfactory (described in terms of burden, stress, coping, depression but also in terms of morbidity and mortality). Changes in social patterns (e.g. split families, long distances between elderly people with dementia and their children, the responsibilities of women in society today, etc) in combination with the difficult economic situation in many municipalities, make the future home-care situation problematic: If the prerequisites for informal care are deteriorating, will the formal system be able to manage the home-care situation?

Most people with mild or moderate dementia live in ordinary homes with or without formal home-care support by choice – either their own or their relatives'. It is difficult to know how different types of formal support are being used by people with dementia and their relatives today. It is likely that the situation differs throughout the country. The governmental working group on dementia has begun a national survey of all municipalities and counties in Sweden aimed at obtaining more information about this issue. The results was presented in 2003.

Special homes and dedicated facilities for dementia care

The Social Services Act provides for a place or apartment in special homes to elderly people in need of assistance. However, in most municipalities today, elderly people must be in very extensive need of care and attention to qualify for a place in a special home. In 2000, roughly 8.5 per cent of those aged 65 years and older were living permanently in special homes; the corresponding figure for those 80 years and over was 22 per cent.

In total, about 119,000 beds are available in assisted living housing for the elderly (not including short-term care), (roughly 17,000 in group living, 29,000 in nursing homes and 73,000 in other assisted living facilities).

The number of people with dementia in these settings is estimated at 38,000: 15,000 in group living for dementia patients and 23,000 in nursing homes. Group living (also called group dwellings or collective living) has been a successful housing arrangement for people with dementia and the municipalities have expanded this kind of housing in recent years. Group living has no standard definition but it usually denotes a small-group home for 6–8 people, in which the residents have their own room, but share communal areas and have access to service and care provided by resident staff around the clock. Special importance is given to staff training and support, and residents are expected to have undergone dementia diagnostic procedures.

The early group living units were mostly set up in small blocks of flats or houses, but in the late 1990s group living units began to become a part of other assisted living facilities. They are, however, still identifiable as separate units. The advantages and disadvantages of this shift are under debate.

In some municipalities, special dementia care units have been integrated within e.g. nursing home facilities. Another trend is to build small homelike units with all the medical and technical resources of a nursing home rather than large assisted living facilities (e.g. large nursing homes). These new assisted living alternatives illustrate that the whole concept of "institution" is changing.

These developments resulted in a heavy expansion of special forms of assisted living housing offered by municipal authorities at the beginning of 1990s, and the standard was improved at the same time. Many of the new facilities were group living homes for dementia patients.

1.6 Are there shortages of relevant specialists (geriatricians, neurologists, psychiatrists, psychologists) or required nursing staff for health or long-term care? If so, what is the impact of the shortages, and do planning and regulatory policies exist for increasing their numbers?

A particular problem confronting elderly care services in Sweden is the difficulty we have – and will increasingly have – in recruiting staff in sufficient numbers. The number of people of working age will decline in the 21st century.

The very high number of people reaching retirement age coupled with the growing number of people in the caring professions on long-term sick leave or being granted disability pensions will result in a great need to recruit more staff, estimated at about 180,000 by 2010. Other figures presented by the labour authorities show that around 25,000 more nurses and 1000 – 4000 more doctors will be needed by 2015. The shortage of geriatricians and family doctors is of particular concern for the future.

The National Board of Health and Welfare presents a report to the government every year on staff recruitment in the health care and social services sector. The report also contains estimates of future recruitment needs.

In mid-2002 the government commissioned ten state authorities to develop a common plan for recruiting staff to health care and social services for care of the elderly and people with

disabilities. The plan is also to include issues concerning education and training of staff, research and the work environment.

2. Health insurance and coverage

2.1 Does dementia change public or private health insurance reimbursement? If yes, is this change affected by the severity of the dementia?

In Sweden public health care is financed by taxes. Elderly care (social services, day centres, long-term care in nursing homes, etc.) is mainly the responsibility of the municipalities. The county councils are responsible for hospital care, diagnostics, drug treatment and the greater part of medical care. Even if some of this care may be provided by private care providers (particularly in long-term care), the government, municipalities and county councils are in charge of how care is financed and organised.

There is no nivellation based on dementia severity in medical or social services, or reimbursement. However, there may be indirect nivellation in the remuneration to caregivers from some municipalities, since this remuneration may be based on the level of functional disability (which is strongly correlated to the severity of dementia). However, the trend in Sweden seems to be away from remunerating caregivers to an increased use of social services. The same pattern may occur regarding the fees for social services, since needs increase with the level of disability.

2.2 Which dementia services are covered under health insurance (public or private) or public provision:

Diagnosis:

Diagnosis is covered under public provision. Patients pay a fee that covers part of the costs, e.g. SEK100–200 per visit. There is an annual ceiling per person of SEK 900 for health care and medical costs.

Drug treatment to slow the progression of dementia:

Mainly public. One-year's treatment of e.g. Donepezil or Rivastigmine costs about SEK10,000 – 12,000. The maximum annual out-of-pocket cost to the patient for all drugs reimbursed by the public system is SEK 1,800. (Currently, responsibility for drug reimbursement is being transferred from national to regional authorities). Tacrine has been taken off the market in Sweden. There is no link between dementia severity and drug reimbursement, but cholinesterase inhibitors are registered only for mild – moderate Alzheimer's Disease, not for severe dementia.

Drug treatment of behavioural symptoms.

See above. Mainly public. Maximum out-of-pocket cost to the patient for all reimbursed drugs is SEK 1,800/year.

Early diagnosis and treatment in specialised centres

Public. See *Diagnosis* above. Specialised centres are mostly located at university clinics and county hospitals. Privately run centres specialising in early diagnosis of dementia are virtually non-existent in Sweden.

2.3 Have there been any significant recent changes in health insurance impacting on dementia patients and their caregivers?

No.

3. Assessment of drug treatments

In Sweden, approximately 15,000 Alzheimer patients are being treated with cholinesterase inhibitors. With regard to the registration conditions for these drugs (accepted for patients with mild and moderate Alzheimer's Disease), about 30 per cent of the potential target population is under treatment (see figures on prevalence etc below).

Since cholinesterase inhibitors are not approved for the treatment of severe AD, they are probably not prescribed for patients suffering from severe dementia as an initial part of their treatment. Whether or not these drugs should be withdrawn when a patient's dementia becomes severe is under debate

Recently, memantine, a NMDA antagonist, was approved for the treatment of severe AD in the EU. Cholinesterase inhibitors are not approved for the treatment of MCI (Mild cognitive impairment).

4. Characteristics and financing of long-term (social) care system

4.2 –4.4 Is the financing and organisation of dementia care isolated or integrated in the health care system, part of the general long-term care system, or under some other arrangement? Is dementia considered as a specific condition in the assessment of needs used by the aged care assessment team determining the level of disability? If not, is there a tendency to consider dementia separately from other dependent conditions? Are there differences in the types of services provided to dementia patients and their caregivers compared to non-dementia clients?

The financing and organisation of dementia care is totally integrated in the health care and social care system in Sweden. This means that there is full access to all the services provided by the public health care system. However, the municipalities have developed special services dedicated to people with dementia and their relatives.

Dementia is regarded as a specific condition in the assessment of needs and a proper diagnosis is a prerequisite for access to e.g. municipal day centres or special group living. Roughly 90 per cent of municipalities run day centres. Where dementia-specific day centres are not available, other forms of day services are organised by the municipalities. Respite care is available both in dementia-specific and non-dementia specific institutions.

4.5- 4.7 Does the coverage of dementia care in nursing homes depend on type of facility where care is provided? severity of dementia (in terms of cognitive, functioning, behaviour), availability of informal care and family caregivers? (e.g. living alone or not). Would a diagnosis of dementia be a factor taken into account to jump the queue for patients who could not be admitted to a psychiatric facility to be admitted in a non specific institutions? Are there incentives in hospitals or in general long-term care institutions to isolate persons with dementia? Are there practices which involve implicit cream-skimming against persons with dementia?

We find questions 4.5–4.7 unclear and are therefore not sure that we can provide relevant answers.

To qualify for assisted living housing in most municipalities today, elderly people must be in very extensive need of care and attention. A permanent move to residential care is in most cases the result of a thorough assessment process that takes into account the severity of dementia and the patient's social network. The availability of permanent residential care varies, and in many municipalities there is a shortage of beds. About 45 per cent of people with dementia live in a nursing home or other assisted living housing that is not dementia-specific. Today many municipalities are in the process of establishing special apartments for persons with dementia in nursing homes or other sheltered living.

4.8 Are specialist diagnosis and treatment centres reimbursed through a fixed price scheme or through a global budget?

Fixed price schemes occur both in municipalities and in counties but diagnosis and treatment are more commonly reimbursed through a global budget.

5. Support for informal caregivers

5.1 Are caregivers actively included in health or care programs directed primarily at the dementia patient? Are there specific support programs aimed at the caregiver? What is the scope of these programs (for example, focussing on education about dementia only, or are other aspects included in the program)?

5.2 For any of the above services available, what is their availability? Is access affected by level of insurance coverage? Is coverage provided through private or public insurance, or social assistance? Is provision adjusted according to various levels of needs? Are there any other significant issues for caregivers' access to support programs?

5.3 Are there any issues for dementia patients' access or eligibility to use respite services?

5.4 Are caregivers of dementia patients offered compensation for care provided to the patient, such as direct or indirect compensation, financial support to help adjusting patients' home? Are there any issues specifically for caregivers of dementia patients in relation to this compensation?

The public health care system offers support for relatives or other informal caregivers in a variety of ways. Most of the specific support programs are free of charge or heavily subsidized. Access to services differs between municipalities. To stimulate and enable municipalities, in collaboration with families and voluntary organisations, to improve and develop support to relatives the Swedish Government earmarked 300 million Swedish kronor for 1999–2001. The National Board of Health and Welfare has recently published a report of effects of this national initiative. Below follows a list of different forms of support that are available in Sweden to the relatives of people with dementia.

- Respite care is available in almost every municipality.
See 1.5 above
- Remuneration, in different forms, is available in about 65 per cent of the municipalities.
Some municipalities offer remuneration to caregivers for at least part of the care they provide in an informal way to a person with dementia. Decisions concerning financial support are often based on an assessment of the nursing load. Remuneration can be offered, for instance at three levels depending on the nursing load. The amount of financial remuneration is rather low: only a few thousand Swedish kronor per month if the caregiver is retired. If the caregiver is of working

age, the payment is often at the same hourly rate as that of a formal caregiver (a home-helper), but remuneration does not reflect the actual number of hours of care provided (see "informal care" above). Opinion is divided on these systems of financial support to caregivers and many municipal social services directors believe it is better to provide formal care in order to decrease the burden on caregivers.

- Daytime activities are available in about 90 per cent of municipalities.
This form of support has improved over the last three years according to the report from the National Board of Health and Welfare and has become more flexible to ease the burden on relatives and informal caregivers. However, the number of people attending these activities has not increased the last few years.
- Respite care at home is available in about 87 per cent of municipalities.
This form of support is often provided by the formal home care system. Home caregivers relieve relatives of their responsibilities for a few hours a day. This form of support has been improved and extended over the last few years.
- Education and training for relatives is available in most municipalities.
This is usually given in small groups to enable caregivers to give and receive mutual support from one another. Many municipalities have expanded this form of support over the last three years.
- Individual conversational support is available in about 75 per cent of municipalities.
This form of support has improved over the last three years. Earlier only about 50 per cent of municipalities could offer this type of support.
- 68 per cent of municipalities have employed a special contact person/support co-ordinator.
This is a new form of support that has been developed with special governmental funds. The support co-ordinator serves as an adviser for relatives.
- 56 per cent of municipalities have started local meeting places for informal caregivers and relatives.
In a relaxed setting, caregivers and relatives meet each other and the support co-ordinator, and also receive information about formal care possibilities.
- 7 per cent of municipalities can offer informal caregivers a holiday break.
- Adjustments to patients' homes and assistive technology.
Grants are available to enable people with functional impairments to make changes to their homes and immediate vicinity that will help them to stay on in their own homes. Typical adjustments include removing thresholds and redoing bathrooms.

Municipalities and county councils share the responsibility for rehabilitation and assistive technology. Assistive technology can be recommended by doctors and occupational therapists and is free of charge for the family. Today we have no figures showing the availability and use of assistive technology designed for people with dementia.

- "Moral support" is also offered by some municipalities in the form of outings and activities, dinners, flowers etc.

PART B Quantitative information

This section address issues of quantitative information about dementia in Sweden. Sources of such information are mainly of two types: register data and research. Per definition, register information are from Swedish sources. The sources from research are also in most cases based on Swedish dementia research and when possible, from population-based studies.

The validity of the data in the attachments is presented and judged in terms of internal and external validity in three levels: poor-moderate-high.

Example: the figures of the number of deaths because of dementia have a high internal validity from our point of view (we have complete register data) but poor external validity since we know that dementia is underrepresented in death certificates.

1. Epidemiological burden

Mortality of dementia - statistics

As in many other countries, dementia as a cause of death is underestimated in death certificates. The National Board of Health and Welfare provide official statistics about the causes of death. In table 1, figures from 2000 are presented, based on ICD-10(1), irrespective of age.

Table 1. Number of deaths in dementia disorders (underlying, main cause of death) according to death certificates in Sweden in 2000

ICD-diagnosis	Male	Female	All
F01.1 Multi-infarct dementia	59	52	111
F01.2 Subcortical vascular dementia	4	5	9
F01.3 Mixed cortical and subcortical vascular dementia	2	0	2
F01.8 Other specified vascular dementia	1	0	1
F01.9 Unspecified vascular dementia	144	214	358
F03.0 Presenile dementia, unspecified	1	2	3
F03.1 Senile dementia, unspecified	350	968	1318
F03.8 Other specified dementia	14	22	36
F03.9 Unspecified dementia	540	1061	1601
F07.0 Organic personality disturbance	10	16	26
F09 Unspecified organic or symptomatic psychiatric disturbances	0	1	1
F00-F09	1125	2341	3466
G30.0 Alzheimer's disease with early onset	8	20	28
G30.1 Alzheimer's disease with late onset	103	215	318
G30.9 Alzheimer's disease, unspecified	150	277	427
G31.1 Senile degeneration of brain, not classified elsewhere	0	1	1
G31.2 Degeneration of nervous system caused by alcohol	1	0	1
G31.8 Other specified degenerative diseases in nervous system	4	0	4
G31.9 Degeneration in nervous system, unspecified	25	18	43
G30-G31	291	531	822

All F00-F09+G30-G31	1416	2872	4288
All deaths	45710	47806	93516
All deaths 65+	37573	42696	80269

Table 2. Death certificates where dementia is mentioned (underlying cause, contributing cause or complication)

ICD-diagnosis	Male	Female	All
F00-F09	2880	5318	8198
G30-G31	611	1028	1639
All F00-F09+G30-G31	3491	6346	9837

As seen in table 1 dementia was the major cause of death in the official statistics in about 4,300 persons during 2000. When all death certificates where dementia is mentioned are included, the figure is about 10,000.

Attached in the Excelfile (Mortality) are the corresponding figures for 1981-2000 shown for 65+ (65 years of age and older)(since tables 1-2 are based on all dementia, irrespective of age, the figures in the attachment are somewhat lower).

Internal validity: high

External validity: poor-moderate.

Two notes are important:

Firstly, the change of diagnostic registration systems influences the figures. In Sweden, the shift from ICD-8 to ICD-9 took place in 1986-1987 and the shift from ICD-9 to ICD-10 in 1996-1997. Therefore, the changes within each period are much more valid than the whole period.

Secondly, there is a coding trend in Sweden to increase the registration of dementia and Alzheimer's disease as an underlying or contributing cause of death. However, there is still an underregistration(see below, table 4).

As seen in the Excelfile, Mortality, if the death patterns are analysed within each ICD-period, the tendency is that dementia and AD as an underlying cause of death increase over time, with age and are higher among women. Despite the problems in the registers, these findings are in line with research (see below).

Mortality of dementia - research

Epidemiological aspects (e.g. prevalence, incidence, mortality, risk factors) of dementia have been analysed extensively in the Kungsholmen Project in Stockholm (2).” DSM-III-R and DSM-IV have been used as diagnostic criteria of dementia and CDR (Clinical Dementia Rating) for staging.

Mortality is analysed for ages 77 and older (3, 4).

Table 3. Mortality per 100 person-years among demented persons in the Kungsholmen Project.

	Male	Female	All
77-84 years of age	29	18	
85+	25	24	
All			23

The figures in table 3 are not adjusted for comorbidity. The mortality rate specific for dementia is 2.4 per 100 person-years of the study population (77+), which means that about 15,800 deaths per year are caused by dementia (about 10,000 female and 6,000 male) in 2000 and about 16,100 in 2002 based on forecasts. If all mortality among demented in this age group was considered, including deaths for other reasons, the number of deaths is about 23,500 in 2000 and 24,100 in 2002 (forecast). If the statistics of dementia as cause of death for the similar available age group (75+) is contrasted to the figures based on research, we can get a rough estimate of the detection rate of dementia as a cause of death (table 4).

Table 4. Dementia as cause of death in 2002 in statistics and based on Swedish research

	Statistics 75+	Research 77+	“Detection rate”
Main cause	4,005	16,100	25%
All causes	9,193	24,100	38%

The “detection rate” of dementia as a contribution to death, as is seen in table 3, is rather low (25-38%). One problem with this comparison is that the death certificates are based on ICD and the research data on DSM. Although these systems are to a great extent congruent, they are, of course, not identical.

Tables 5-6 indeed illustrate that dementia is linked to an increased risk of death (3, 4).

Table 5. Relative risk (RR) for death: demented vs non-demented

	Male	Female	All
77-84 years of age	3.6	4.5	
85+	1.7	2.4	
All			2.7

Table 6. Mortality during 5 years.

	Demented	Non-demented
77-84 years of age	34%	15%
85+	90%	68%
All	70%	35%

After controlling for sociodemographic variables and comorbidity, 14% of all deaths in this age-class could be attributed to dementia with a risk of death among demented subjects twice as high as that for non-demented people. Seventy per cent of the demented died during the five years after diagnosis.

Mortality risk ratios were 2.0 (95% confidence interval 1.5-2.7) for Alzheimer's disease (AD) and 3.3 (95% confidence interval 2.0-5.3) for Vascular dementia. Even among the oldest old, dementia shortens life (3, 4).

Internal validity: moderate (differences due to ICD-version)

External validity: poor- moderate (since the detection rate in death certificates, although improving, is still low).

Incidence

In order to calculate incidence figures for dementia and AD in relation to gender and severity, different sources need to be used, which will make the figures somewhat inconsistent. Some assumptions must also be made. Based on age-specific and sex-specific incidence figures from pooled European data (5), the annual incidence of dementia and AD respectively of male and female are shown in the Excelfile, Incidence for the period 1980-2001. A division of incidence at different stages of severity is undertaken. There is a meta-analysis for incidence of mild and moderate (but not severe) dementia (6), but since there are so great differences in the incidence figures as compared to Fratiglioni et al (5), we chose not to use stage specific incidence figures. However, it is to be expected that the incidence in moderate dementia is lower than in mild dementia, and is lowest in severe dementia (i.e. due to mortality). The incidence is higher particularly among older women.

Internal validity: moderate (no nationwide registers available)

External validity: moderate (since the figures depend on incidence source).

Prevalence

There is no overall population-based single study that completely describes the prevalence of dementia in relation to subtypes, age-classes, gender, and severity. Therefore, different sources must be used, which will make the figures somewhat inconsistent. Some assumptions must therefore be made.

1. The major source for the prevalence figures is based on the Eurodem paper from 1990 (7) (table 7). There are meta-analyses and similar published later that include papers from the 1990s, such as by Fratiglioni et al (8) and Lobo et al (9), but since the Eurodem paper includes sex-specific prevalence figures, that source was chosen. When applied to the period 1980-2001, the overall dementia agreement is 97-101% between the figures by Fratiglioni et al and Eurodem, indicating that the Eurodem figures still are valid. There are, however, differences between specific age-classes. The prevalence is higher in Fratiglioni et al among particularly 95+ (about 45%), based on larger samples of this age class, which may influence the total number of demented persons in the future as the number of very old people grows.

The recent prevalence report by Lobo et al (9) also includes age- and sex-specific prevalence figures of both dementia and AD, but the resulting total number of demented with these figures is much lower, about 110,000 in 2000 as compared to around 130,000 with Fratiglioni

et al (8) and Eurodem. Other frequently cited meta-analyses by Jorm et al (10) and Ritchie et al (11) were excluded since they focus only on moderate-severe dementia.

Table 7. Age and sex-specific prevalence of dementia according to Eurodem (7)

Age-class	Male (%)	Female (%)
60-64	1,6	0,5
65-69	2,2	1,1
70-74	4,6	3,9
75-79	5	6,7
80-84	12,1	13,5
85-89	18,5	22,8
90-94	32,1	32,2
95+	31,6	36

2. The AD proportion is assumed to be 50-70% of all dementias in most reviews (8). However, when the proportion of AD among the overall dementia population is calculated using the above mentioned Lobo et al's figures and used on the demographics of the Swedish elderly population, the proportion of AD is higher among women (about 71%) than in men (53%). These proportions are used in the calculations when the occurrence of AD is calculated. The proportion of AD in different age classes was rather similar in women, while there was a higher proportion of AD among the oldest old men (85+), but we nevertheless assume that the 53% and 71% figures for men and women respectively were similar, since the numbers of very old men in these studies were so small.

3. The distribution of severity is rather similar in AD and dementia as a whole. Patients with Vascular dementia tend to suffer from more severe dementia from a cross-sectional perspective (12), and consequently the overall dementia population also suffer from more severe dementia than the AD-population. However, the differences are small – the differences are less than 5% (12) or even smaller (13), and therefore we assume that the distributions are similar in AD and overall dementia.

4. The distribution of severity according to age is based on findings from the Kungsholmen Project for the age-groups 75-84 and 85+ (12). For the age-group 65-74 extrapolation was used. There is support for the view that the proportion of severely demented is higher among the oldest demented people as compared to the younger (12, 13).

Based on the assumptions above, with all its limitations, the following matrix (table 8) for the distribution of the dementia population in relation to age, gender, and severity was used in the attached tables.

Table 8. Matrix for the calculation of dementia prevalence.

CDR	65-74		75-84		85+	
	male	female	male	female	male	female
1	50%	50%	40%	30%	30%	10%
2	30%	30%	40%	45%	50%	65%
3	20%	20%	20%	25%	20%	25%
	100%	100%	100%	100%	100%	100%

In the Excelfile, prevalence, the prevalence in relation to gender, age-class, and severity of overall dementia and AD during 1980-2001 is presented. The number of demented persons in the age-class 60-64 is also included, assuming the same distribution in severity as for the age-class 65-74.

Internal validity: moderate (no nationwide registers available)

External validity: moderate (since the figures depend on different combined sources).

Disability

Disability of the demented is derived from the findings of Katz' index of ADL (14) among the demented in the Kungsholmen Project. These findings were assumed to be valid for the national Swedish dementia population. The seven steps in Katz are here defined in three levels of disability: independent, partial disability and complete disability. However, the methodological problems to describe disability in relation to subtypes, age-classes and gender are the same as for prevalence, see above. In the Kungsholmen Project, 19% of the demented persons were independent, 66% partially dependent, and 15% completely dependent (4).

Internal validity: moderate (no nationwide registers available)

External validity: moderate (since the figures depend on different combined sources).

MCI

The number of persons with Mild Cognitive Impairment (MCI) is even more difficult to estimate since the epidemiological literature is sparse. However, based on the incidence of dementia and AD respectively and the assumption that all patients with manifest dementia and AD respectively come from the "MCI-pool" with an annual conversion of 15 % from MCI to dementia/AD, it can be roughly estimated that the number of persons with MCI (overall) is about 175,000 and MCI-AD to about 125,000 persons. These figures must, however, be judged with care; they just offer a hint of the number of MCI-persons.

2. Treatment and care

Distribution in care organisation

It is not easy to estimate how this dementia population is distributed in the care organisation, but in a cost-of illness study of dementia in Sweden from the National Board of Health and Welfare (Socialstyrelsen)(15), this issue has been analysed extensively. If the main option in this report is applied to the 2000 dementia population, the situation is as in table 9.

Table 9. Distribution in the care organisation of the Swedish dementia population in 2000.

Care alternative	Number	Per cent
Nursing home	23,000	17%
Group Living	14,000	10%
Other sheltered livng	38,000	28%
All sheltered living	75,000	56%
Home care/ordinary living	58,000	44%

All

133,000

The proportion of demented living in institutions (sheltered living) is high in Sweden (more than half of the dementia population).

Ambulatory care

There are no national statistics available for dementia disorders of out-care visits (such data are, however, underway and will be available from the year of 2001). However, dementia as a registered diagnosis is probably underreported. There are data from local studies where all the visits to physicians have been registered with diagnoses, and thus the number of visits by demented persons to physicians can be calculated. Such figures were also used in the cost of illness study(15). Based on such local data, a demented person visits a physician 1-2 times per year.

Another approach is to analyse visits to physicians by a population defined as demented or suffering from cognitive decline. Such data will probably result in higher figures than register-based figures. Nevertheless, in the Excelfile, ambulatory visits 1 (all demented) –2 (demented in ordinary living), we have used the latter approach, that is we have looked at the registered number of visits to physicians of a study population that are defined as suffering from mild-moderate-severe cognitive decline. These data are obtained from the SNAC-project (16). SNAC (Swedish National study on Aging and Care) is a longitudinal population-based project, aiming to describe the elderly and the care of the elderly in Sweden from two perspectives: a population-based perspective and a care system perspective. Although the population-based questionnaire is much bigger the care system questionnaire, they are integrated, making it possible to describe how the elderly population and the care system interact. Both questionnaires also include a comprehensive set to analyse the utilization of care resources and also assessments of informal care. Currently, the baseline assessments from the care system perspective are available. Here we have used some of the findings from SNAC in Stockholm (urban) (17) and Nordanstig (rural) (18). Based on register data, these persons with cognitive decline made 2-4 visits per year to a physician, which is twice as much as with the other approach.

In Sweden, long-term care is a legally defined form of living. It means that demented that e.g. live in a nursing home may also make out-care visits to physicians or physicians may make “home visits” to the nursing home. In the figures in the Excelfile, ambulatory visits 1, all demented are included. If only the visits to physicians by demented who live in ordinary living are of interest, the figures can be reduced by about 55% (see table 9), since the proportion of demented persons living in sheltered living (“institutions”) is so high. Furthermore, since the number of visits vary between demented persons living in ordinary living and sheltered living according to SNAC-data (those in ordinary living have more visits) (17, 18), the figures are adjusted according to that. In the Excelfile, ambulatory visits 1-2, the figures are extrapolated to the Swedish dementia population for the period 1980-2001, both for the whole dementia population (ambulatory visits 1) and the non-institutionalized proportion (ambulatory visit 2).

The total number of visits in out-care was about 21.3 million in 2000 (to be compared with the total number of estimated visits by demented (about 833,000 or 620,000; all demented and demented in ordinary living respectively).

The disadvantages with the figures are that

- a. they are estimated figures and not true register data
- b. they are based on “cognitive decline” and not a set dementia diagnosis
- c. they include persons that are known by the care system, and therefore the figures are probably higher than for a general population with cognitive decline
- d. the figures do not compensate for comorbidity.

When the results therefore are extrapolated they are probably too high. This conclusion is also supported by the few local studies as mentioned above with the other approach (number of registered visits with a dementia diagnosis), where the figures are lower (1-2 visits a year). These problems can at least partly be compensated for when we get results from the population-based part of SNAC.

There are no data to differentiate between visits between diagnostic procedures and other types of visits. Data from the Linköping study (19) indicate that only half of the elderly with mental disorders (including dementia) have notations about such conditions in their medical records. Of the severely demented, 60% had notes about cognitive decline in the records(20). The corresponding figures for moderate and mild dementia were 15% and 24%, respectively.

When the national register for our care visits becomes available, the quality of data will increase considerably, although the risk of underreporting dementia must be considered.

Internal validity: moderate (no nationwide registers available)

External validity: poor (see above).

Hospital care

In Sweden, the long-term care of the elderly including dementia has been the responsibility of the municipalities since 1992 (the Ädel reform). Therefore the amount of hospital care is rather low after 1992. Before 1992, a large amount of the long-term care took place in geriatric clinics or similar and thus was registered as hospital care. Since 1992, the majority of nursing homes have been the responsibility of the municipalities (they can be run by municipalities themselves or by private providers). Care at geriatric and psychiatric hospitals are in most cases due to diagnostic procedures or short-term care because of problems in home care or in the institutions (sheltered living).

In the Excelfile, hospital care 1-3, the corresponding figures for the period before 1987 (ICD-8), 1987-1996 (ICD-9) and since 1997 (ICD-10) are presented.

The same two notes that were made regarding mortality are also of importance with regard to hospital care:

Firstly, the change of the diagnostic registration system influences the figures. In Sweden, the shift from ICD-8 to ICD-9 took place in 1986-1987 and the shift from ICD-9 to ICD-10 in 1996-1997. Therefore, the changes within each period are much more valid than the whole period.

Secondly, there is a coding trend in Sweden to increase the registration of dementia and AD as a reason for care. However, there is still an under-registration.

Hospital care 1 includes care of all demented persons (principal diagnosis and other diagnosis).

Hospital care 2 includes data on all hospitalisations for all demented persons.

Hospital care 3 includes data on AD-patients hospitalizations (principal diagnosis and other diagnosis).

Internal validity: high

External validity: moderate (underreporting)

Drug treatment

The choline-esterase inhibitors are neither approved for severe dementia nor for MCI (mild cognitive impairment). The potential maximum target population is therefore persons with mild and moderate AD. If 50-60 % of the 100,000 persons with mild and moderate dementia suffer from AD, the maximum target population is about 50-60,000 persons. Based on the annual sales of choline-esterase inhibitors in 2001, the number of persons under treatment is about 16,000 persons, that is about 30% of the potential maximum target population for treatment. The figures are presented in the Excelfile (drug). Note that in Sweden, these drugs are coded as N06DA and not N07DA.

Internal validity: high

External validity: moderate (no figures concerning severity are available)

Formal home care/support and informal care

There are no national diagnosis-based register data concerning the amount of formal and informal care to demented persons. Therefore, the figures presented in the Excelfile, formal care and informal care are estimates, mainly based on a recently published Swedish study on formal and informal care to demented people(21). The results from this study, which are seen in table 10, are extrapolated to the whole of Sweden and to the period of 1980-2001. The figures are based on the estimated number of demented persons living in ordinary dwellings (see table 9) and it is assumed that there is one principal caregiver to each demented person. The characteristics of the principal caregivers are based on the Swedish study(21). Of the total formal care (table 10), the greatest part was day care (23 hours per 28 days) while social services constituted 8 hours per 28 days, i.e. 2 hours per week. This figure also included non-users of formal home care, which may explain the rather low figures. On the other hand, since the number of hours are calculated on the estimated dementia population in ordinary living, the non-user figures should logically be included.

Table 10. Formal and informal care to home-dwelling demented persons: hours per 28 days (maximum 28*24 hours=672 hours) (from (21)).

Severity	Formal care	Total informal care	Informal care	
			PADL*+	Supervision
Mild	21	231	130	101
Moderate	44	414	162	252
Severe	93	259	206	53
All	35	299	148	151

*=Personal ADL

**=Instrumental ADL

As seen in table 10, the relation between formal and informal care is about 1:4 if only informal support in terms of PADL and IADL is considered and about 1:8.5 when supervision is also included. The supervision component is as large as PADL and IADL support together.

The total amount of informal care is about 10 hours per day. Interestingly, the total amount of care is highest in moderate dementia and not in severe dementia, mainly because of the need for supervision. This is probably an effect of behavioural disturbances, which peak in moderate dementia.

Most informal carers are women: in the Swedish study the female proportion was 62% (and about 2/3 of these women were spouses) (21).

In the Swedish COI-study(15), which is based on results from the Kungsholmen Project and some other sources, the situation in the year of 2000 was analysed.

Of 133,000 demented persons in 2000, 75,000 lived in institutions/sheltered living and the other 58,000 in their own dwellings (table 11).

Table 11. Living situation for non-institutionalized demented persons in Sweden 2000.

Severity	Living alone	Not living alone	All
Mild	29,000	13,000	42,000
Moderate	7,300	3,200	10,500
Severe	3,200	2,300	5,500
All	39,500	18,500	58,000

Of the 58,000 home-dwelling demented persons, there is a grey area since some of these may be non-users of both formal and informal care. Therefore the figures above may be over-estimates to some extent. Population-based data concerning these aspects are underway, which will be presented later.

Internal validity: moderate-poor

External validity: moderate-poor

Respite care

Respite care can be of both institutional and non-institutional types. There are few studies on respite institutional care for demented persons. However, different kinds of short-term care (respite care, palliative care, rehabilitation) are mainly the responsibility of the municipalities. The dynamics of respite care are difficult to catch in cross-sectional studies, since the turnover in respite care is so high. Local data about institutional respite care will be available soon.

Although the objectives of day care for demented persons are to improve the situation for the demented people themselves, it also has an effect on caregivers, which can be described in terms of respite care. In studies of day care for demented people in Sweden, it was concluded that although day care is advantageous for the demented patients, the benefits may be even greater for the informal caregivers/spouses(22, 23), indicating the respite care effect of day care. Other studies of day care in Sweden indicate that although day care may reduce the need for institutional care, mainly due to the respite effect(22), savings in total costs have not been shown, since the costs of day care itself “consumes” the savings(24).

In the Swedish COI-study, demented persons were assumed to visit day care for demented persons about 2-3 times every week. In general the mean stay time at each session was 4-5 hours.

There is support for this amount of day care in Swedish day care studies(24, 25). However, currently it is not clear how large a proportion of the demented persons in ordinary living that

attend day care. In COI-study it was assumed that about 10% of the home-dwelling demented persons attended day care. This figure was based on the situation in the beginning of the 1990s. The figure is probably higher today (see the qualitative section of the report), but there is also a great variation between municipalities. Another reason for the uncertainty lies in there being no distinctly defined concept of day care. There are, indeed, special day care units that focus on demented persons, but demented people may also attend day care focused on physical rehabilitation and they may also attend rather low-staffed “day centers”, where meals are served and some activities also take place, but there is no specific program for those with dementia. In the attachment we have used the Swedish figures mentioned above and extrapolated them to the whole period, being aware of the risk of an underestimate.

Internal validity: moderate-poor

External validity: poor

Long-term institutional care

The institutional concept is vague in Sweden today (from a legal aspect it is named “Särskilt boende”(special living)) and a lot of terms are used (nursing home, group living, service houses, home for the aged, sheltered living etc.). This is not only due to administrative reasons; also in physical terms there are difficulties in identifying a building, a ward or a room as e.g. “a nursing home bed”, since the content of care, the medical-technical resources, the staffing ratio and level of competence etc have changed the prerequisites for care so much. After the “Äldereform” in 1992, when the municipalities took over the main responsibility for long-term care (named as mentioned above “Särskilt boende”), in legal terms, the service is more of a form a living than a care option. There are no nationwide registers specifically focusing on demented persons regarding the long-term care for demented people. However, in various reports, the situation has been highlighted in different ways.

In a nationwide survey from the National Board of Health and Welfare(26), where about 20% of the long-term institutions in Sweden are described, care for demented persons was a major activity in about 80% of the units. However, the activity pattern is differentiated and in many units, various forms of care intentions were practiced. In 2.6% of the units, special care for demented people with problematic behaviours were practiced.

Staffing ratio

In the above mentioned report (26), the overall staffing ratio in long-term care was estimated at 0.74, and of this figure, about 88% were assistant nurses or similar and 7% were registered nurses.

In different types of long-term care, the staffing ratio was as in table 12. The specified care alternatives in this survey (group living, nursing home etc) covers about 50% of the different kinds of long-term alternatives (there is a great variation in the definitions and naming of long-term alternatives).

Table 12. Staffing ratio in long-term care of the elderly in 2001 (adapted from the National Board of Health and Welfare (26).

	Group Living	Elderly Living	Service houses	Nursing homes	Homes for the aged	All
Proportion with cognitive decline	92%	70%	45%	87%	68%	70%
Staffing ratio(SR)						
SR: assistant nurses or similar	0,91	0,62	0,39	0,73	0,68	0,65
SR: Reg. Nurses	0,04	0,05	0,02	0,12	0,05	0,05
SR: others	0,06	0,05	0,04	0,04	0,03	0,04
SR: all	1,01	0,72	0,45	0,89	0,76	0,74

As seen in table 13, the proportion of persons with cognitive decline (mild-moderate-severe) was high in all types of long-term care, but highest in Group Living, where the staffing ratio was also highest (see also the Excelfile, LTC supply).

The change in staffing ratio over time is illustrated in table 13 from Sundsvall(27), where several studies of the care for the elderly have been undertaken.

Table 13. Staff density in different forms of institutional care in Sundsvall, Sweden.

	1980	1993	1996	1998
Home for the aged	0,31	na*	na*	0,76
Group Living	na*	na*	na*	1,07
Nursing Home	0,66	1,19	1,17	1,05

*na=data not available.

Between 1980 and 1993, the staffing ratio increased considerably in nursing homes, while the ratio during the 90s was rather unchanged and now there is perhaps a trend towards a decrease.

Internal validity: moderate

External validity: moderate

Proportion of demented persons

There is a discussion in Sweden regarding the proportion of demented people in long-term institutions. In the report from the National Board of Health and Welfare(26), the proportion of persons with cognitive decline was estimated at about 70%. Based on an extensive analysis of the change in care structure during the 1990s, the COI-study from the National Board of Health and Welfare tried to describe the institutional care organisation for the elderly in a rather detailed way (table 14). There are about 119,000 beds in Sweden for long-term care/living for the elderly. The number of demented people in long-term care was estimated as 75,000 in 2000 (63% of the number of beds and about 56% of the demented in Sweden).

Table 14. Long-term care/living for the elderly in Sweden in 2000.

	Number of beds	Proportion of demented	Number of demented
Nursing home	29 000	80%	23 000
Group Living	14 000	100%	14 000
Other sheltered living	76 000	50%	38 000
Total	119 000	63%	75 000

Group Living is a form of care specially designed for demented people and therefore the proportion of demented is estimated at 100% (however, there is some discrepancy, see table 12 above). About 56% of the Swedish dementia population live in institutional care.

Most institutions are run by the municipalities, but the number of privately run institutions is increasing. In 1993, 5.4% of the residents in institutions lived in privately run institutions, a figure that had increased to 12.3% in 2001(28) (table 15). The total number of elderly (65+) that permanently live in long-term care today is about 119,000. The situation before 1992, when the Ädel reform took place, is very difficult to compare with the situation after the reform and therefore the figures in the Excelfile Lterm care starts with 1993 (statistics from 1992, the year of the reform, are problematic). Furthermore, since 1998, the presentation of the number of persons living in sheltered living is divided into permanent long-term care and short-term care/respite care. The figures in the Excelfile include permanent care with adjusted figures for permanent care for the period 1993-1997 (based on the proportion of short-term/long-term care for 1999-2001). The demented proportion is estimated to be 63% (see above).

Table 15. Proportion of residents in long term care run by private institutions or similar.

Year	Proportion
1993	5,40%
1994	7,10%
1995	8,30%
1996	9,30%
1997	10,20%
1998	9,80%
1999	9,70%
2000	11,60%
2001	12,30%

Internal validity: moderate

External validity: moderate

Length of stay

There are no register data about the length of stay for demented persons in long-term care. One reason is, as mentioned above, that the long-term stay in legal terms is a form of living rather than medical care (and therefore not part of the hospital care statistics). However, as part of the Kungsholmen Project, there is a longitudinal survival analysis study underway where demented persons' length of stay in institutional care before death is analysed and compared to non-demented during 14 years. These data will be available within a few months. In a report from the National Board of Health and Welfare, it was estimated that for all residents, about 50% stayed for a shorter period than 2 years and about 20% longer than 5

years (26). If these proportions are transformed into an estimated length of stay (and short-term care is excluded) it will be about 3 years.

Internal validity: poor (no data available yet)

External validity: poor

3. Social outcomes and quality of care.

Time from diagnosis to long-term institutional care

There are no register data about the time from diagnosis to long-term institutional care. There may be a period of several years from the early signs of cognitive decline during the state of MCI (Mild Cognitive Impairment) before the diagnostic criteria for dementia are fulfilled (according to e.g. DSM III-R, DSMIV, or ICD-10). In addition there maybe a period of several years between diagnosis and institutionalization. Ideally, such studies are based on incident cases of dementia in a longitudinal population-based studies. Such data will be available from the Kungsholmen Project in the future, but currently, data is only available for prevalent cases. The forthcoming study mentioned above, where length of stay in long-term care is analysed, will also include information about the time from inclusion to institutionalization of the prevalent cases. Roughly, if it is assumed that a person with dementia lives 10 years from diagnosis to death and that the period spent in long-term care is 3 years (see above), the time from diagnosis to institutional care is about 7 years. However, since a diagnosis of dementia is set earlier today than 10 years ago, a dynamic approach must be used when the period 1980-2001 is analysed.

In an early study(12), it was found that more severe cases had a higher institutionalization rate, which was also the case for vascular dementia compared to AD. Fifty-five percent of the demented subjects and only 3% of the non-demented were institutionalized. The institutionalized demented subjects were affected mostly by moderate-severe dementia (88.6%), while the noninstitutionalized were affected more often by a questionable-mild form (68.3%). In another study(29), the attributable risk percentage of institutionalization during a 3-year follow-up due to dementia was 61%.

Time from diagnosis to death

In one study of incident cases in the Kungsholmen Project, (3), a 77+ old cohort including incident dementia cases was used to evaluate the impact of dementia on the risk of death, taking into account other chronic conditions potentially related to death, and contrasting and Vascular dementia (VaD) during a five year follow-up (see also above section about mortality). 70% of the dementia cases died during the five years after diagnosis, with a mortality rate specific for dementia of 2.4 per 100 person-years. After controlling for sociodemographic variables and comorbidity, 14% of all deaths could be attributed to dementia with a risk of death among demented subjects twice as high as that for non-demented people. Mortality risk ratios were 2.0 (95% confidence interval 1.5-2.7) for AD and 3.3 (95% confidence interval 2.0-5.3) for VaD. The forthcoming study (see above), where time to and time in institutional care until death, is analysed will also provide information of the whole course.

Treatment information and quality of care

Data on these aspects are not available on a national or population level since such information usually demands a controlled study design of an intervention. Such interventions have been conducted at various places in Sweden.

Drug treatment

In a recently published thesis (30), the drug use patterns of elderly in the Kungsholmen area in Stockholm were analysed in a population-based study. Demented persons used more psychotropic drugs than non-demented (52.1% vs 36.5% respectively) in 1994-1996 and particularly in institutions the use was high (31). Another study showed similar results (45% and 38% respectively(32). In a report from the National Board of Health and Welfare the findings were similar: neuroleptics were used in 38.5% of the residents in nursing homes (33). The range was high; range 17-75%. There are also great risks of potential drug-disease interactions (34). These findings are in line with the experiences presented at a conference in 1995 organized by the Medical Products Agency(35) and in a report from SBU (The Swedish Council on Technology Assessment in Health Care) (36). The National Board of Health and Welfare have therefore launched a project to improve the use of drugs in the elderly (28).

Restraints

The purpose of different kinds of restraints is, in most cases, to prevent dangerous events, such as falls. Nevertheless, the use of restraints influences integrity and autonomy, and from a legal point of view, restraints are doubtful. In an ideal care situation, there would be no need for restraints if the number of staff were high. However, since this is seldom the case, there is a use of restraints that must be analysed. In a report, The National Board of Health and Welfare analysed the use of restraints in two representative counties in Sweden with a focus on demented persons (37). There are different kinds of restraints, such as in-locking, individual physical restraints (such as different kinds of belts to prevent falling from wheelchairs) and different kinds of alarms.

It was found that in institutions for demented, the outer door of the institution was locked in 81% of the institutions. The proportion of demented that could open the door independently was low, 6%. There were alarms on the outer doors in 23%. Individual restraints were frequent, about 44%. The use of restraints has also been illuminated in studies from Northern Sweden(38-41). Restraints were used in 24%-29% of the patients in institutions, where a great majority of persons are demented.

Behaviour

The management of different behaviours (e.g. screaming, wandering, aggressiveness) of patients with dementia is one of the critical issues in dementia care, irrespective of whether it is in the natural home setting (42) or in institutions (43). Such behaviours are frequent. In a Swedish mixed (institutionalized and non-institutionalized) non-population-based study group (44), a high mental nursing load was reported in 23-24%. In a comprehensive study of institutionalized elderly people in Northern Sweden(45), wandering was reported in 17% of the residents (of whom 40% were demented), care resistance in 17%, and aggressiveness in 23%. Population-based figures, where most persons are non-institutionalized) are lower: 7% (46). Psychiatric conditions, which may cause behaviours regarded as problematic, are also frequent: psychotic symptoms (14%), depression 25% and anxiety (23%) (47). Major depression has been diagnosed in 12% of demented persons(48). However, it must be noted

that the term “behaviour” must be viewed from different perspectives. Concepts such as “behavioural disturbances” or “inappropriate behaviour” are defined from the perspective of caregivers (family members, staff) and not the patients. Even if such behaviours indeed are problematic for caregivers and are one of the major reasons for institutionalization of demented persons and exhaustion among caregivers (42, 49) (50), we should avoid terms such as “disturbances”. A more neutral term, “Behavioral and Psychological Symptoms of Dementia” (BPSD) has been presented by the International Psychogeriatric Association (IPA). The focus should be on interpreting the behaviour (35), aiming to improve the situation for both patients and caregivers. Such interventions and programs have been conducted in Sweden and have shown to be advantageous (51-59).

Group Living

The Group-Living concept was introduced in Sweden in the 1980s a care alternative, where demented persons live in home-like conditions with around-the-clock staff (60-62). With different evaluation approaches, Group-Living has shown to be cost-effective (61) and to improve care (44, 60, 63-66).

Day Care

Day care can be conducted in different settings and with various contents. Day care for demented persons in Sweden, like Group-living, has often been located in home-like settings, where demented persons spend 5-6 hours per day. The care is often based on principles of individual care plans, integrity promoting activities, and mutuality. Swedish evaluations have shown that Day care reduces institutionalization (22), while the issue of cost-effectiveness is more complicated (24). Despite the effects on the demented patients (22, 23), it also has positive effects on staff (67, 68) and on the situation for caregivers (23).

Malnutrition

Saletti evaluated the nutritional status of all individuals in assisted accommodation in three Swedish municipalities(69) by using the Mini Nutritional Assessment (MNA) scale (0-30 points). MNA <17, i.e., malnutrition, was noted in 36% of the study population (21% of individuals in service houses, 33% of those in home for the aged, 38% of those in Group-living for demented persons and 71% of those in nursing homes. The corresponding values for MNA scores 17-23.5 (risk for malnutrition) were 49, 51, 57, and 29%, respectively.

Impact on caregivers: e.g. satisfaction with support, satisfaction with role.

On a population-based level, extensive information is available from the Kungsholmen Project. Here are some examples.

In an early study(70, 71) it was shown that in a comparison between relatives of demented persons living at home and in institutions, the relatives of institutionalized subjects were less frequently spouses and had more problems with their physical health, but both groups had similar subjective feeling of stress.

When caregivers were compared with relatives of elderly, mentally healthy persons living at home in the same district, they had a higher subjective burden and also a higher use of psychotropic drugs. Spouses were the most stressed. About 10% of caregivers also reported abusive behaviour(71).When the demented person is institutionalized, the burden decreases(42). Jansson et al interviewed children of demented and non-demented(72) persons. Eighty-nine per cent of the children in the study group and 76% of the children in the

reference group were not willing to care for their parents in the family home during the progression of the disease, even if they were employed as caregivers. The circle model is an approach to improve the situation for caregivers(73). In another study (74), it was found there were more significant differences between female caregivers and female non-caregivers than between male caregivers and male non-caregivers, with females caring for a demented elder suffering the most strain. Their strain was exhibited by health problems, conflicts in the family, strained relations with family and others, a less positive outlook, and limitations in social support because of the caregiving situation. When investigating the group of male caregivers and male non-caregivers, it was found that males caring for a demented elderly person experienced a lack of positive outlook and a need for social support.

4. Expenditures and costs

Drug treatment

In 2001 the total expenditures for the acetyl-choline esterase inhibitors was about 192 million SEK (10 SEK is approximately 1 €and 1 US\$). The expenditures have increased continuously after the launch of the drugs, and the trend for the first 6 months in 2002 is the same (see Excellfile, drug exp). Note that in Sweden, these drugs are coded as N06DA and not N07DA.

Internal validity: high

External validity: high

Cost for long-term care (home care and nursing homes):

please see also section below about cost of illness

The out of pocket costs to patient have varied a lot in Sweden since this is part of the municipalities' responsibilities. However, this year the Swedish Parliament decided that a maximum fee guarantee was introduced July 1st 2002. Moreover, the rules for personal financial remain were defined. The new rules make it clear that municipalities may charge 1516 to 1579 SEK a month at the most for all kinds of elderly care. All clients are guaranteed a minimum financial remain of 4087 SEK for singles, and 3324 SEK for individuals living as couples after the client's payments for housing and care.

Benefits to caregivers

There is no specific nationwide economical support system for demented patients' informal caregivers. However, in some municipalities there is remuneration to caregivers to pay for at least part of their informal care with the demented person. The decisions about this financial support are often based on an assessment of nursing load of the demented patient, and the remuneration can, for instance, be divided in three levels depending on the nursing load. The sums are rather low, roughly a few thousand SEK/month if the caregiver is retired. If the caregiver is of working age, the payment is often on the same level per hour as a formal caregiver (a home-helper), but there is no remuneration for the real amount of hours (see above about informal care). There is a varied opinion concerning these support systems to caregivers and many of the leaders of the municipalities' social services think that it is better to provide formal care in order to decrease the burden of the caregivers. However, since the amount of informal care to demented persons is so large, it is obvious that the formal care system will have difficulties in replacing informal care completely.

For terminal palliative care (that is, not specifically for demented persons), it is possible for caregivers of working age to be off work but still paid for up to 60 days paid (with the same economical level as for sick leave).

Cost of illness studies

In an early cost of illness study of dementia in Sweden, the gross costs were calculated to about 31 billion SEK(75). The results of an update and more comprehensive analysis are shown in table 16(15). In this report (in Swedish) there is also an extensive sensitivity analysis and a discussion about methodological issues.

Table 16. Gross costs of dementia in Sweden in 2000 (base case). 10 SEK≈1€and ≈1 US\$.

Care	Cost (million SEK)
Nursing home	10 074
Group Living	6132
Other sheltered living	9432
Day Care for demented	390
Emergency room visits	117
Emergency hospital care	278
Geriatric hospital	276
Psychiatric hospital	300
Physician visits	80
Other out care visits	80
Drug use	386
Informal care mild dementia	3528
Informal care moderate dementia	1113
Informal care severe dementia	743
Formal home care mild dementia	2604
Formal home care moderate dementia	1260
Formal home care severe dementia	1496
Production losses (patients)	194
Diagnostics (incident cases)	125
Adjustments for double counting	-190
Total	38 418 million

This represents an annual cost per demented person of about 290,000 SEK. The costs of informal care represent a conservative opportunity cost approach. About 80% of the costs are within the municipalities' care responsibilities and the institutional costs represent about 65% of the costs.

The cost figures in table 15 represent gross costs (costs for persons with dementia). The net costs (costs due to the dementia disorders) were estimated to about 27 billion SEK (about 200,000 per case and year).

Internal validity: moderate

External validity: moderate

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Appendix

A selection of textbooks and reports in Swedish by Swedish dementia specialists that can be used as guidelines for dementia care:

Adolfsson R, Sandman PO, Wikander B. Äldrelev. Hagmans förlag, Stockholm, 1991.

Adolfsson R, Sandman PO, Åström S, Winblad B. Demenssjukdomar och äldrepsykiatri. Hagmans förlag, Stockholm, Sweden, 1988.

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Medicinska Forskningsrådet. Demenssjukdom: diagnostik, tidig behandling och anhörigas insatser Medicinska Forskningsrådet, Stockholm, 1995.

Svenska Läkarsällskapet och SPRI. När minnet sviker. Om demens och demensliknande tillstånd. Läkardagarna i Örebro 1994. Svensk Medicin 1994:2. Stockholm, Sweden, 1994.

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Marcusson J, Passant U, Wahlund L-O, Wallin A. Minnesstörningar och demens. Ljungskile, det mångkulturella förlaget, 1999.

Socialdepartementet; Dnr S2002/7722/ST

OECD case study on dementia

SWEDEN

Anders Wimo, Catharina Morthenson Ekelöf

PART C. Tables

Anders Wimo, 2003

Table 1. Classification

Diagnostic code:
International Classification of Diseases

ICD-version	Alzheimer's disease	Dementia
ICD-8	290.0, 290.1	
ICD-9	290.0 290.1 331.0	290 294.1 331.0
ICD-10	F00 G30	F00-03 G30

Table 2A-2C. Demographics

Validity Internal: high
 External: high
 Source: Statistics Sweden

Table 2A. Demographics. Male

SWEDEN Country population in thousands

Male

	60-64	65-74	75-84	85+
1980	232,930	382,190	175,586	33,153
1981	237,774	382,163	179,750	34,268
1982	238,492	381,967	184,761	35,276
1983	239,662	380,584	189,820	36,251
1984	239,293	378,543	195,701	37,420
1985	229,659	384,852	200,322	38,476
1986	221,860	388,239	204,410	39,910
1987	216,576	387,931	208,632	41,311
1988	211,938	387,541	212,221	42,214
1989	207,328	386,892	215,879	44,081
1990	203,986	386,687	217,544	45,453
1991	201,553	384,666	219,062	47,225
1992	199,996	381,516	220,588	49,095
1993	196,875	379,620	220,975	50,547
1994	195,909	376,811	222,032	53,408
1995	195,455	368,232	228,992	55,511
1996	196,743	361,229	234,000	57,222
1997	199,351	356,758	236,311	59,039
1998	205,446	350,874	238,615	60,659
1999	213,249	346,841	239,759	62,062
2000	219,449	345,105	241,551	62,976
2001	226,539	345,797	242,246	64,266

Table 2B. Demographics: Female

**Country population in
thousands
Female**

<i>Year</i>	60-64	65-74	75-84	85+
1980	245,782	443,097	260,934	67,139
1981	251,475	443,438	268,307	69,777
1982	253,261	443,516	276,583	72,988
1983	254,747	442,069	284,844	76,425
1984	255,671	439,582	293,333	80,036
1985	245,700	447,481	299,051	83,929
1986	237,522	451,915	304,730	87,905
1987	231,510	452,123	310,547	92,466
1988	227,567	451,668	315,190	95,615
1989	222,788	450,989	319,927	99,852
1990	219,760	450,645	322,225	103,642
1991	216,976	448,843	323,892	108,059
1992	215,140	445,270	325,644	112,424
1993	210,592	443,317	325,399	116,259
1994	208,932	440,491	325,799	121,574
1995	206,234	430,349	334,354	125,894
1996	206,550	421,139	340,271	129,435
1997	207,470	414,451	342,102	133,713
1998	212,286	406,781	343,318	137,409
1999	218,114	400,345	343,631	139,917
2000	223,028	395,229	344,031	141,995
2001	228,538	392,911	343,383	143,461

Table 2C. Demographics: All

SWEDEN	Country population in thousands: ALL					
	60-64	65-74	75-84	85+	65+	0+
1980	478,712	825,287	436,520	100,292	1 362,099	8 317,937
1981	489,249	825,601	448,057	104,045	1 377,703	8 323,033
1982	491,753	825,483	461,344	108,264	1 395,091	8 327,484
1983	494,409	822,653	474,664	112,676	1 409,993	8 330,573
1984	494,964	818,125	489,034	117,456	1 424,615	8 342,621
1985	475,359	832,333	499,373	122,405	1 454,111	8 358,139
1986	459,382	840,154	509,140	127,815	1 477,109	8 381,515
1987	448,086	840,054	519,179	133,777	1 493,010	8 414,083
1988	439,505	839,209	527,411	137,829	1 504,449	8 458,888
1989	430,116	837,881	535,806	143,933	1 517,620	8 527,036
1990	423,746	837,332	539,769	149,095	1 526,196	8 590,630
1991	418,529	833,509	542,954	155,284	1 531,747	8 644,119
1992	415,136	826,786	546,232	161,519	1 534,537	8 692,013
1993	407,467	822,937	546,374	166,806	1 536,117	8 745,109
1994	404,841	817,302	547,831	174,982	1 540,115	8 816,381
1995	401,689	798,581	563,346	181,405	1 543,332	8 837,496
1996	403,293	782,368	574,271	186,657	1 543,296	8 844,499
1997	406,821	771,209	578,413	192,752	1 542,374	8 847,625
1998	417,732	757,655	581,933	198,068	1 537,656	8 854,322
1999	431,363	747,186	583,390	201,979	1 532,555	8 861,426
2000	442,477	740,334	585,582	204,971	1 530,887	8 882,792
2001	455,077	738,708	585,629	207,727	1 532,064	8 909,128

Table 3A. Mortality (underlying cause).

Validity Internal: moderate
External: poor-moderate
Source: National board of Health and Welfare (Sweden)

Year	Sex Age group ICD version	Mortality: Alzheimer's disease:underlying cause						Mortality: dementia:underlying cause					
		Rate per 100,000 population for 12 month period						Rate per 100,000 population for 12 month period					
		Males			Females			Males			Females		
		65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+
1980	ICD8							3,93	22,44	103,59	3,84	31,45	131,01
1981	ICD8							4,97	33,77	142,39	7,67	38,92	188,44
1982	ICD8	see Dementia (separation AD and other dementia not possible)						9,42	40,05	129,41	7,89	38,91	175,11
1983	ICD8							7,61	37,38	167,77	7,23	43,46	242,28
1984	ICD8							4,22	39,95	198,18	8,62	53,96	315,73
1985	ICD8							7,86	44,44	171,29	6,31	57,40	311,04
1986	ICD8							9,57	51,39	170,95	7,78	57,64	292,14
1987	ICD9	10,82	70,21	236,39	7,74	68,91	409,16	13,14	94,42	293,03	9,07	82,89	477,90
1988	ICD9	11,35	75,09	340,02	12,61	80,55	530,62	14,96	98,85	409,46	13,72	95,89	604,00
1989	ICD9	13,69	91,10	308,24	10,19	106,12	569,92	15,75	109,32	380,09	11,08	116,83	632,33
1990	ICD9	17,32	103,36	377,51	16,64	114,93	633,93	20,68	132,90	440,06	18,63	126,14	723,36
1991	ICD9	15,30	100,78	446,71	19,12	109,89	660,37	19,45	123,22	535,19	22,23	126,29	731,22
1992	ICD9	15,40	104,17	404,90	16,33	121,93	647,67	18,79	130,10	477,57	18,34	137,64	721,14
1993	ICD9	16,29	94,21	421,51	15,98	111,51	646,31	18,92	125,92	525,88	18,46	131,48	732,89
1994	ICD9	15,34	88,94	386,71	17,88	115,79	592,85	19,57	113,32	465,59	19,23	136,67	690,40
1995	ICD9	17,99	98,00	438,86	16,77	115,43	652,21	24,16	125,49	536,18	19,98	132,70	737,06
1996	ICD9	16,18	106,70	386,75	16,44	105,24	632,13	21,39	133,05	480,78	19,26	121,25	747,27
1997	ICD10	7,24	40,40	82,57	10,05	40,15	101,84	21,17	144,16	677,79	20,58	153,29	878,59
1998	ICD10	6,78	28,21	106,94	7,31	43,48	105,49	20,63	177,29	840,45	20,70	180,62	1071,10
1999	ICD10	8,31	37,21	104,30	13,13	52,99	152,89	24,37	205,28	992,50	22,80	223,31	1340,66
2000	ICD10	6,65	48,20	150,35	8,80	57,88	161,04	23,99	218,15	1087,67	26,90	209,41	1306,79

Table 3B. Mortality (contributing cause).

Validity Internal: moderate
 External: poor-moderate
 Source: National board of Health and Welfare (Sweden)

Year	Sex Age group ICD-version	Mortality: Alzheimer's as contributing cause Rate per 100,000 population for 12 month period						Mortality: dementia as contributing cause Rate per 100,000 population for 12 month period					
		Males			Females			Males			Females		
		65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+
1980	ICD8							22,02	196,18	642,89	16,28	159,97	799,78
1981	ICD8							22,50	157,60	507,26	17,37	150,40	740,60
1982	ICD8	see Dementia (separation AD and other dementia not possible)						24,34	174,48	606,81	16,69	149,02	741,08
1983	ICD8							26,23	191,15	766,14	13,55	176,69	811,17
1984	ICD8							20,81	167,57	667,83	15,65	143,90	778,47
1985	ICD8							18,34	182,31	708,86	16,91	164,08	883,12
1986	ICD8							20,95	173,45	696,55	13,79	154,69	819,40
1987	ICD9	17,78	176,25	797,82	16,15	170,00	863,78	21,64	200,95	874,16	17,48	190,81	924,76
1988	ICD9	25,02	207,67	864,41	18,37	190,50	993,19	29,14	239,04	948,22	20,58	207,12	1062,31
1989	ICD9	13,69	198,55	862,16	11,52	169,10	979,19	18,59	238,73	973,41	15,73	194,29	1074,35
1990	ICD9	18,36	196,57	864,48	12,20	171,30	1010,35	25,08	234,87	987,33	15,53	197,46	1093,89
1991	ICD9	13,48	185,06	787,67	11,34	176,13	1026,92	19,71	244,61	940,89	13,56	200,27	1113,84
1992	ICD9	18,01	211,53	894,93	12,30	173,66	1089,43	25,58	263,85	1063,12	15,21	208,15	1191,02
1993	ICD9	17,08	185,25	925,31	15,08	182,17	1002,26	27,06	244,13	1099,94	19,58	221,18	1126,45
1994	ICD9	15,07	162,98	790,73	14,03	154,18	955,29	25,38	225,73	935,02	17,65	186,43	1072,18
1995	ICD9	14,50	170,28	822,63	13,32	155,42	853,44	21,48	237,68	934,64	18,14	190,26	975,48
1996	ICD9	14,26	163,72	839,15	11,27	155,05	898,45	24,40	241,47	1032,53	17,38	191,51	1031,61
1997	ICD10	8,64	49,33	94,61	5,51	39,57	104,12	44,01	339,78	1372,77	30,40	273,46	1422,01
1998	ICD10	4,24	38,32	130,33	5,60	41,73	111,39	31,09	293,52	1366,77	24,35	235,77	1271,75
1999	ICD10	6,31	56,44	132,01	6,94	52,70	134,14	36,40	335,72	1337,99	23,79	262,61	1427,92
2000	ICD10	6,94	58,17	145,56	7,29	51,48	151,82	35,55	349,88	1441,16	24,64	284,44	1498,34

Table 4A. Incidence (per 100,000 of age class population and year).

Validity Internal: moderate
 External: moderate
 Source: See text

Sex Age group	Incidence (per 100,000 of age class population and year)											
	Alzheimer's Disease						Dementia					
	Male			Female			Male			Female		
	65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+
1980	183	928	2072	291	1572	3743	404	1699	3057	344	2143	4518
1981	184	929	2072	291	1578	3747	406	1699	3057	345	2148	4524
1982	185	930	2073	292	1585	3755	408	1702	3057	346	2154	4528
1983	186	929	2072	293	1587	3755	410	1700	3057	347	2155	4532
1984	186	930	2073	293	1591	3758	411	1701	3057	347	2159	4536
1985	184	928	2074	291	1593	3759	406	1699	3058	345	2161	4535
1986	182	931	2072	290	1598	3762	404	1703	3056	343	2165	4537
1987	182	933	2073	290	1602	3763	403	1707	3058	343	2169	4537
1988	181	936	2073	289	1611	3763	401	1712	3057	342	2176	4538
1989	180	943	2074	289	1622	3763	400	1722	3058	341	2186	4539
1990	184	949	2071	292	1631	3766	408	1732	3056	345	2193	4546
1991	187	953	2072	294	1637	3768	413	1738	3057	348	2199	4549
1992	189	956	2071	295	1646	3769	416	1744	3056	350	2207	4555
1993	191	960	2072	296	1651	3769	419	1750	3057	351	2211	4555
1994	192	962	2072	297	1656	3772	421	1752	3057	352	2216	4561
1995	191	953	2072	296	1640	3782	419	1738	3057	351	2202	4568
1996	190	948	2070	295	1631	3787	417	1731	3056	350	2193	4576
1997	189	948	2068	295	1627	3791	416	1730	3054	349	2190	4580
1998	189	945	2066	295	1623	3802	416	1726	3052	350	2187	4590
1999	188	946	2063	295	1620	3809	415	1726	3049	349	2184	4599
2000	188	961	2059	295	1651	3816	414	1751	3046	349	2211	4606
2001	187	971	2057	294	1674	3828	412	1768	3045	349	2231	4612

Table 4B. Incidence (crude data).

Validity Internal: Moderate
 External: Moderate
 Source: See text

Sex Age group	Incidence (crude data)												Dementia		
	Alzheimer's disease						Dementia						Male	Female	All
	Male			Female			Male			Female					
	65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+			
1980	698	1630	687	1289	4102	2513	1546	2983	1013	1525	5591	3033	5542	10149	15691
1981	702	1669	710	1292	4235	2614	1553	3055	1048	1529	5763	3157	5656	10449	16104
1982	705	1718	731	1296	4385	2741	1560	3144	1079	1534	5957	3305	5782	10797	16579
1983	707	1763	751	1294	4519	2870	1561	3227	1108	1532	6139	3464	5897	11134	17031
1984	705	1819	776	1289	4666	3008	1556	3329	1144	1526	6332	3630	6029	11488	17517
1985	707	1860	798	1304	4765	3155	1564	3404	1177	1543	6463	3806	6145	11812	17957
1986	707	1902	827	1312	4869	3307	1568	3480	1220	1552	6597	3988	6268	12137	18405
1987	704	1947	856	1310	4976	3480	1562	3561	1263	1549	6735	4195	6386	12479	18865
1988	700	1987	875	1306	5077	3598	1554	3632	1291	1544	6859	4339	6477	12742	19219
1989	697	2035	914	1302	5188	3757	1549	3717	1348	1539	6992	4532	6614	13063	19677
1990	713	2065	941	1314	5254	3903	1577	3768	1389	1556	7068	4711	6734	13334	20069
1991	721	2087	978	1319	5304	4072	1590	3807	1443	1563	7123	4915	6841	13601	20442
1992	721	2110	1017	1314	5361	4238	1588	3846	1500	1558	7187	5121	6935	13865	20800
1993	723	2122	1047	1312	5372	4382	1591	3866	1545	1556	7195	5295	7003	14046	21049
1994	722	2135	1107	1308	5396	4585	1587	3890	1633	1552	7218	5546	7110	14316	21426
1995	702	2182	1150	1274	5485	4762	1544	3979	1697	1511	7362	5751	7220	14624	21843
1996	685	2219	1185	1244	5548	4901	1508	4050	1748	1475	7463	5922	7306	14860	22166
1997	674	2239	1221	1222	5566	5069	1485	4087	1803	1448	7492	6125	7375	15065	22440
1998	662	2256	1253	1200	5573	5224	1459	4118	1851	1423	7508	6307	7429	15238	22667
1999	653	2267	1280	1180	5567	5329	1439	4139	1893	1398	7506	6434	7470	15338	22809
2000	648	2321	1297	1165	5679	5419	1428	4230	1919	1381	7606	6541	7576	15528	23104
2001	646	2353	1322	1156	5749	5491	1426	4282	1957	1370	7662	6617	7664	15649	23314

Table 5A. Prevalence of Alzheimer's Disease (rate per 100,000 population per 12-month period)

Validity Internal: moderate
 External: moderate
 Source: See text

Prevalence: Alzheimer's Disease

Rate per 100,000 population per 12-month period

Year	Mild								Moderate								Severe							
	Males				Females				Males				Females				Males				Females			
	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+
1980	424	870	1592	3462	178	861	1988	1813	254	522	1592	5770	107	517	2982	11787	170	348	796	2308	71	345	1657	4534
1981	424	874	1593	3460	178	865	1994	1817	254	524	1593	5766	107	519	2990	11808	170	349	796	2306	71	346	1661	4542
1982	424	877	1595	3458	178	870	2000	1820	254	526	1595	5763	107	522	3000	11829	170	351	798	2305	71	348	1667	4550
1983	424	880	1594	3461	178	873	2002	1822	254	528	1594	5768	107	524	3002	11840	170	352	797	2307	71	349	1668	4554
1984	424	881	1595	3459	178	876	2005	1824	254	529	1595	5764	107	526	3008	11854	170	353	797	2306	71	350	1671	4559
1985	424	874	1592	3454	178	865	2008	1823	254	524	1592	5756	107	519	3012	11852	170	349	796	2303	71	346	1673	4559
1986	424	869	1597	3462	178	858	2012	1825	254	521	1597	5771	107	515	3019	11860	170	348	798	2308	71	343	1677	4562
1987	424	867	1602	3456	178	854	2017	1825	254	520	1602	5761	107	513	3025	11861	170	347	801	2304	71	342	1680	4562
1988	424	864	1609	3459	178	851	2025	1825	254	519	1609	5764	107	510	3037	11864	170	346	804	2306	71	340	1687	4563
1989	424	863	1623	3454	178	847	2035	1826	254	518	1623	5757	107	508	3053	11867	170	345	811	2303	71	339	1696	4564
1990	424	876	1636	3464	178	867	2044	1829	254	526	1636	5774	107	520	3066	11891	170	350	818	2309	71	347	1703	4573
1991	424	885	1644	3462	178	881	2050	1831	254	531	1644	5769	107	529	3075	11902	170	354	822	2308	71	353	1709	4578
1992	424	890	1652	3464	178	889	2059	1834	254	534	1652	5773	107	534	3088	11922	170	356	826	2309	71	356	1716	4585
1993	424	895	1660	3461	178	895	2063	1834	254	537	1660	5768	107	537	3095	11921	170	358	830	2307	71	358	1719	4585
1994	424	899	1663	3460	178	901	2068	1838	254	539	1663	5767	107	541	3102	11944	170	359	832	2307	71	361	1723	4594
1995	424	895	1644	3461	178	896	2053	1842	254	537	1644	5768	107	537	3080	11972	170	358	822	2307	71	358	1711	4605
1996	424	892	1634	3467	178	891	2044	1846	254	535	1634	5779	107	534	3065	12000	170	357	817	2311	71	356	1703	4615
1997	424	890	1633	3477	178	887	2040	1849	254	534	1633	5794	107	532	3060	12018	170	356	816	2318	71	355	1700	4622
1998	424	890	1628	3486	178	889	2037	1855	254	534	1628	5810	107	533	3055	12055	170	356	814	2324	71	356	1697	4637
1999	424	888	1629	3497	178	887	2034	1860	254	533	1629	5828	107	532	3051	12088	170	355	814	2331	71	355	1695	4649
2000	424	886	1662	3512	178	887	2063	1864	254	532	1662	5853	107	532	3094	12118	170	354	831	2341	71	355	1719	4661
2001	424	883	1684	3519	178	884	2085	1869	254	530	1684	5866	107	530	3128	12146	170	353	842	2346	71	354	1738	4672

Table 5B. Prevalence of Alzheimer's Disease (Crude data per 12 months period) gender, age, severity

Validity Internal: moderate
 External: moderate
 Source: See text

Prevalence: Alzheimer's Disease

Crude data per 12 months period

Year	Mild								Moderate								Severe							
	Males				Females				Males				Females				Males				Females			
	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+
1980	988	3326	2795	1148	436	3816	5187	1218	593	1996	2795	1913	262	2290	7780	7914	395	1330	1397	765	175	1527	4322	3044
1981	1008	3339	2863	1186	446	3837	5349	1268	605	2003	2863	1976	268	2302	8023	8239	403	1335	1431	790	179	1535	4457	3169
1982	1011	3350	2948	1220	450	3859	5533	1328	607	2010	2948	2033	270	2316	8299	8634	404	1340	1474	813	180	1544	4610	3321
1983	1016	3349	3025	1254	452	3861	5701	1392	610	2010	3025	2091	271	2317	8552	9049	406	1340	1512	836	181	1544	4751	3480
1984	1015	3337	3121	1294	454	3852	5883	1460	609	2002	3121	2157	272	2311	8824	9487	406	1335	1561	863	182	1541	4902	3649
1985	974	3362	3190	1329	436	3873	6005	1530	584	2017	3190	2215	262	2324	9008	9948	390	1345	1595	886	174	1549	5004	3826
1986	941	3374	3264	1382	422	3879	6132	1604	564	2025	3264	2303	253	2327	9198	10426	376	1350	1632	921	169	1552	5110	4010
1987	918	3364	3343	1428	411	3863	6262	1687	551	2018	3343	2380	247	2318	9393	10968	367	1346	1672	952	164	1545	5219	4218
1988	899	3350	3414	1460	404	3842	6382	1745	539	2010	3414	2433	242	2305	9573	11344	359	1340	1707	973	162	1537	5318	4363
1989	879	3340	3503	1523	395	3822	6511	1823	527	2004	3503	2538	237	2293	9767	11850	352	1336	1751	1015	158	1529	5426	4558
1990	865	3388	3560	1575	390	3906	6585	1896	519	2033	3560	2624	234	2344	9878	12324	346	1355	1780	1050	156	1563	5488	4740
1991	855	3406	3601	1635	385	3956	6641	1979	513	2044	3601	2725	231	2374	9961	12861	342	1362	1801	1090	154	1582	5534	4947
1992	848	3396	3644	1701	382	3960	6704	2062	509	2038	3644	2834	229	2376	10056	13403	339	1358	1822	1134	153	1584	5587	5155
1993	835	3397	3668	1749	374	3969	6714	2132	501	2038	3668	2915	224	2381	10070	13860	334	1359	1834	1166	150	1587	5595	5331
1994	831	3386	3693	1848	371	3971	6738	2234	498	2031	3693	3080	223	2382	10107	14521	332	1354	1846	1232	148	1588	5615	5585
1995	829	3296	3765	1921	366	3854	6864	2319	497	1978	3765	3202	220	2312	10296	15072	331	1319	1882	1281	146	1542	5720	5797
1996	834	3223	3825	1984	367	3751	6954	2389	501	1934	3825	3307	220	2251	10431	15532	334	1289	1912	1323	147	1501	5795	5974
1997	845	3175	3859	2052	368	3677	6979	2472	507	1905	3859	3421	221	2206	10469	16070	338	1270	1929	1368	147	1471	5816	6181
1998	871	3121	3885	2114	377	3617	6992	2548	523	1873	3885	3524	226	2170	10489	16565	348	1249	1942	1410	151	1447	5827	6371
1999	904	3079	3905	2170	387	3549	6988	2602	543	1847	3905	3617	232	2130	10483	16913	362	1232	1953	1447	155	1420	5824	6505
2000	930	3058	4014	2212	396	3507	7097	2647	558	1835	4014	3686	238	2104	10646	17206	372	1223	2007	1474	158	1403	5914	6618
2001	961	3055	4079	2262	406	3473	7161	2681	576	1833	4079	3770	243	2084	10742	17425	384	1222	2039	1508	162	1389	5968	6702

Table 6A. Prevalence of Dementia (rate per 100,000 population per 12-month period): gender, age, severity

Validity Internal: moderate
 External: moderate
 Source: See text

Prevalence: Dementia

Rate per 100,000 population per 12-month period

Year	Mild								Moderate								Severe							
	Males				Females				Males				Females				Males				Females			
	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+
1980	800	1642	3003	6532	250	1213	2800	2554	480	985	3003	10887	150	728	4200	16602	320	657	1502	4355	100	485	2333	6385
1981	800	1648	3005	6528	250	1219	2808	2559	480	989	3005	10880	150	731	4212	16631	320	659	1503	4352	100	488	2340	6397
1982	800	1655	3010	6524	250	1226	2817	2563	480	993	3010	10873	150	735	4226	16661	320	662	1505	4349	100	490	2348	6408
1983	800	1660	3007	6529	250	1230	2819	2566	480	996	3007	10882	150	738	4229	16677	320	664	1503	4353	100	492	2349	6414
1984	800	1663	3009	6526	250	1234	2825	2569	480	998	3009	10876	150	740	4237	16696	320	665	1505	4350	100	494	2354	6421
1985	800	1648	3004	6517	250	1219	2828	2568	480	989	3004	10861	150	731	4243	16693	320	659	1502	4344	100	488	2357	6421
1986	800	1640	3013	6533	250	1209	2834	2570	480	984	3013	10888	150	725	4251	16704	320	656	1506	4355	100	484	2362	6425
1987	800	1636	3023	6521	250	1203	2840	2570	480	982	3023	10869	150	722	4260	16706	320	654	1512	4348	100	481	2367	6425
1988	800	1631	3036	6525	250	1198	2852	2571	480	979	3036	10876	150	719	4278	16710	320	652	1518	4350	100	479	2376	6427
1989	800	1629	3062	6517	250	1194	2866	2571	480	977	3062	10861	150	716	4300	16714	320	652	1531	4345	100	477	2389	6429
1990	800	1653	3088	6536	250	1221	2878	2577	480	992	3088	10894	150	733	4318	16748	320	661	1544	4357	100	488	2399	6441
1991	800	1671	3102	6532	250	1241	2888	2579	480	1002	3102	10886	150	745	4331	16763	320	668	1551	4354	100	497	2406	6447
1992	800	1679	3117	6536	250	1253	2899	2583	480	1008	3117	10893	150	752	4349	16791	320	672	1558	4357	100	501	2416	6458
1993	800	1689	3132	6529	250	1261	2906	2583	480	1013	3132	10882	150	757	4359	16791	320	675	1566	4353	100	504	2422	6458
1994	800	1695	3138	6528	250	1270	2913	2588	480	1017	3138	10880	150	762	4369	16823	320	678	1569	4352	100	508	2427	6470
1995	800	1689	3102	6530	250	1261	2892	2594	480	1013	3102	10883	150	757	4337	16862	320	676	1551	4353	100	505	2410	6485
1996	800	1684	3084	6542	250	1255	2878	2600	480	1010	3084	10903	150	753	4317	16901	320	673	1542	4361	100	502	2399	6500
1997	800	1679	3081	6559	250	1250	2873	2604	480	1008	3081	10932	150	750	4310	16927	320	672	1540	4373	100	500	2395	6510
1998	800	1678	3072	6577	250	1252	2869	2612	480	1007	3072	10961	150	751	4303	16979	320	671	1536	4385	100	501	2391	6530
1999	800	1675	3073	6598	250	1249	2864	2619	480	1005	3073	10996	150	749	4297	17026	320	670	1537	4399	100	499	2387	6548
2000	800	1672	3135	6626	250	1250	2906	2626	480	1003	3135	11044	150	750	4358	17067	320	669	1568	4418	100	500	2421	6564
2001	800	1667	3177	6640	250	1245	2937	2632	480	1000	3177	11067	150	747	4406	17107	320	667	1589	4427	100	498	2448	6580

Table 6B Prevalence of dementia (rate per 100,000 population per 12-month period) Gender and age

Validity: Internal: moderate

External: moderate

Source: See text

Prevalence: dementia

Rate per 100,000 population per 12-month period

All kinds of severity

	Males				Females			
	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+
1980	1600	3284	7508	21773	500	2426	9332	25541
1981	1600	3297	7513	21759	500	2438	9360	25587
1982	1600	3309	7526	21746	500	2451	9391	25632
1983	1600	3321	7517	21765	500	2460	9397	25656
1984	1600	3326	7523	21752	500	2468	9415	25686
1985	1600	3297	7510	21722	500	2438	9428	25682
1986	1600	3280	7532	21776	500	2418	9448	25699
1987	1600	3272	7558	21738	500	2407	9467	25702
1988	1600	3262	7589	21752	500	2396	9506	25708
1989	1600	3258	7654	21723	500	2387	9555	25714
1990	1600	3306	7719	21787	500	2442	9595	25765
1991	1600	3341	7755	21772	500	2483	9625	25789
1992	1600	3359	7792	21786	500	2505	9665	25832
1993	1600	3377	7830	21765	500	2522	9686	25832
1994	1600	3391	7845	21761	500	2539	9709	25881
1995	1600	3378	7755	21765	500	2523	9639	25942
1996	1600	3367	7709	21806	500	2509	9594	26001
1997	1600	3359	7702	21865	500	2499	9578	26042
1998	1600	3357	7680	21923	500	2505	9562	26122
1999	1600	3350	7683	21993	500	2497	9548	26193
2000	1600	3344	7838	22088	500	2500	9685	26257
2001	1600	3334	7943	22134	500	2490	9791	26319

Table 6C. Prevalence of Dementia (Crude data per 12 months period): gender, age, severity

Validity Internal: moderate
 External: moderate
 Source: See text

Prevalence: Dementia

Crude data per 12 months period

Year	Mild								Moderate								Severe							
	Males				Females				Males				Females				Males				Females			
	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+
1980	1863	6276	5274	2166	614	5375	7305	1715	1118	3765	5274	3609	369	3225	10958	11146	745	2510	2637	1444	246	2150	6088	4287
1981	1902	6299	5402	2237	629	5405	7534	1785	1141	3780	5402	3728	377	3243	11301	11605	761	2520	2701	1491	251	2162	6278	4463
1982	1908	6320	5562	2301	633	5436	7792	1871	1145	3792	5562	3836	380	3261	11689	12160	763	2528	2781	1534	253	2174	6494	4677
1983	1917	6319	5707	2367	637	5438	8030	1961	1150	3792	5707	3945	382	3263	12045	12745	767	2528	2854	1578	255	2175	6692	4902
1984	1914	6295	5889	2442	639	5425	8285	2056	1149	3777	5889	4070	384	3255	12428	13363	766	2518	2944	1628	256	2170	6904	5139
1985	1837	6343	6018	2507	614	5454	8458	2155	1102	3806	6018	4179	369	3273	12687	14011	735	2537	3009	1672	246	2182	7049	5389
1986	1775	6367	6159	2607	594	5463	8637	2259	1065	3820	6159	4345	356	3278	12956	14684	710	2547	3079	1738	238	2185	7198	5648
1987	1733	6347	6308	2694	579	5441	8820	2377	1040	3808	6308	4490	347	3265	13230	15448	693	2539	3154	1796	232	2176	7350	5941
1988	1696	6321	6442	2755	569	5412	8988	2458	1017	3792	6442	4591	341	3247	13482	15978	678	2528	3221	1836	228	2165	7490	6145
1989	1659	6302	6609	2873	557	5383	9170	2568	995	3781	6609	4788	334	3230	13756	16690	663	2521	3305	1915	223	2153	7642	6419
1990	1632	6392	6717	2971	549	5502	9275	2670	979	3835	6717	4951	330	3301	13913	17357	653	2557	3358	1981	220	2201	7729	6676
1991	1612	6426	6795	3085	542	5572	9353	2787	967	3856	6795	5141	325	3343	14029	18114	645	2570	3398	2056	217	2229	7794	6967
1992	1600	6407	6875	3209	538	5578	9442	2904	960	3844	6875	5348	323	3347	14163	18877	640	2563	3437	2139	215	2231	7868	7260
1993	1575	6410	6921	3300	526	5590	9456	3003	945	3846	6921	5501	316	3354	14184	19521	630	2564	3460	2200	211	2236	7880	7508
1994	1567	6388	6968	3487	522	5592	9490	3146	940	3833	6968	5811	313	3355	14235	20452	627	2555	3484	2324	209	2237	7908	7866
1995	1564	6219	7103	3625	516	5428	9668	3266	938	3732	7103	6041	309	3257	14502	21229	625	2488	3552	2416	206	2171	8057	8165
1996	1574	6081	7216	3743	516	5283	9794	3365	944	3649	7216	6239	310	3170	14691	21876	630	2433	3608	2496	207	2113	8162	8414
1997	1595	5991	7281	3873	519	5179	9830	3482	957	3595	7281	6454	311	3107	14745	22634	638	2396	3640	2582	207	2072	8192	8705
1998	1644	5889	7330	3989	531	5094	9849	3589	986	3534	7330	6649	318	3056	14773	23331	657	2356	3665	2660	212	2038	8207	8973
1999	1706	5809	7368	4095	545	4999	9843	3665	1024	3486	7368	6825	327	3000	14764	23822	682	2324	3684	2730	218	2000	8202	9162
2000	1756	5770	7573	4173	558	4940	9996	3728	1053	3462	7573	6955	335	2964	14994	24234	702	2308	3787	2782	223	1976	8330	9321
2001	1812	5764	7696	4267	571	4892	10086	3776	1087	3458	7696	7112	343	2935	15129	24543	725	2306	3848	2845	229	1957	8405	9439

Table 6D. Prevalence of Dementia (Crude data per 12 months period): gender, age.

Validity Internal: moderate
 External: moderate
 Source: See text

Year	Prevalence: dementia										
	Crude data per 12-month period										
	All kinds of severity								All ages		
	Male				Female				Men	Women	All
	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+			
1980	3727	12551	13184	7219	1229	10750	24351	17148	36681	53479	90159
1981	3804	12598	13504	7456	1257	10810	25112	17854	37363	55033	92397
1982	3816	12640	13905	7671	1266	10871	25975	18708	38032	56821	94853
1983	3835	12639	14268	7890	1274	10876	26767	19608	38632	58525	97156
1984	3829	12591	14722	8140	1278	10850	27617	20558	39282	60303	99585
1985	3675	12687	15045	8358	1229	10909	28194	21555	39764	61887	101650
1986	3550	12733	15397	8691	1188	10926	28790	22591	40370	63495	103865
1987	3465	12694	15769	8980	1158	10882	29400	23766	40909	65206	106114
1988	3391	12642	16105	9182	1138	10824	29961	24581	41320	66503	107823
1989	3317	12604	16523	9576	1114	10765	30568	25676	42020	68124	110144
1990	3264	12783	16792	9903	1099	11004	30917	26704	42742	69723	112465
1991	3225	12852	16988	10282	1085	11143	31176	27868	43347	71272	114619
1992	3200	12815	17187	10696	1076	11156	31473	29042	43898	72747	116645
1993	3150	12821	17302	11001	1053	11179	31519	30032	44274	73783	118058
1994	3135	12776	17419	11622	1045	11185	31632	31464	44951	75326	120278
1995	3127	12439	17758	12082	1031	10856	32227	32659	45406	76773	122179
1996	3148	12163	18040	12478	1033	10567	32647	33655	45829	77901	123730
1997	3190	11982	18202	12909	1037	10358	32767	34821	46282	78983	125265
1998	3287	11779	18325	13298	1061	10188	32828	35894	46689	79971	126661
1999	3412	11618	18420	13649	1091	9999	32809	36649	47100	80547	127647
2000	3511	11540	18933	13910	1115	9880	33321	37283	47894	81599	129493
2001	3625	11528	19241	14225	1143	9784	33621	37758	48618	82305	130923

Table 6E. Prevalence of Dementia (Crude data per 12 months period): severity.

Validity Internal: moderate
 External: moderate
 Source: See text

SWEDEN **Country population in thousands**

Severity

	Mild	Moderate	Severe	All
1980	30588	39465	20107	90159
1981	31193	40576	20628	92397
1982	31824	41825	21205	94853
1983	32377	43030	21750	97156
1984	32946	44313	22326	99585
1985	33388	45445	22818	101650
1986	33860	46663	23342	103865
1987	34298	47935	23881	106114
1988	34640	48891	24292	107823
1989	35120	50183	24841	110144
1990	35708	51383	25374	112465
1991	36172	52571	25876	114619
1992	36553	53737	26355	116645
1993	36782	54587	26689	118058
1994	37160	55907	27210	120278
1995	37388	57111	27680	122179
1996	37574	58095	28061	123730
1997	37749	59084	28432	125265
1998	37915	59977	28768	126661
1999	38030	60614	29002	127647
2000	38494	61570	29429	129493
2001	38865	62304	29754	130923

Table 7A. Disability in dementia (rate per 100,000 population per 12-month period): gender, age, severity

Validity Internal: moderate
 External: moderate
 Source: See text

Disability in dementia

Rate per 100,000 population per 12-month period

Year	No disability								Partly disabled								Complete disability							
	Males				Females				Males				Females				Males				Females			
	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+
1980	304	624	1427	4137	95	461	1773	4853	1056	2167	4956	14370	330	1601	6159	16857	240	493	1126	3266	75	364	1400	3831
1981	304	626	1427	4134	95	463	1778	4861	1056	2176	4958	14361	330	1609	6177	16887	240	494	1127	3264	75	366	1404	3838
1982	304	629	1430	4132	95	466	1784	4870	1056	2184	4967	14352	330	1618	6198	16917	240	496	1129	3262	75	368	1409	3845
1983	304	631	1428	4135	95	467	1785	4875	1056	2192	4961	14365	330	1624	6202	16933	240	498	1127	3265	75	369	1410	3848
1984	304	632	1429	4133	95	469	1789	4880	1056	2195	4965	14356	330	1629	6214	16952	240	499	1128	3263	75	370	1412	3853
1985	304	626	1427	4127	95	463	1791	4880	1056	2176	4957	14336	330	1609	6222	16950	240	494	1127	3258	75	366	1414	3852
1986	304	623	1431	4137	95	459	1795	4883	1056	2165	4971	14372	330	1596	6235	16961	240	492	1130	3266	75	363	1417	3855
1987	304	622	1436	4130	95	457	1799	4883	1056	2160	4989	14347	330	1589	6248	16963	240	491	1134	3261	75	361	1420	3855
1988	304	620	1442	4133	95	455	1806	4885	1056	2153	5009	14356	330	1582	6274	16967	240	489	1138	3263	75	359	1426	3856
1989	304	619	1454	4127	95	454	1815	4886	1056	2150	5052	14337	330	1575	6306	16972	240	489	1148	3258	75	358	1433	3857
1990	304	628	1467	4140	95	464	1823	4895	1056	2182	5094	14380	330	1612	6333	17005	240	496	1158	3268	75	366	1439	3865
1991	304	635	1473	4137	95	472	1829	4900	1056	2205	5118	14369	330	1639	6353	17021	240	501	1163	3266	75	372	1444	3868
1992	304	638	1480	4139	95	476	1836	4908	1056	2217	5142	14379	330	1654	6379	17049	240	504	1169	3268	75	376	1450	3875
1993	304	642	1488	4135	95	479	1840	4908	1056	2229	5168	14365	330	1664	6393	17049	240	507	1174	3265	75	378	1453	3875
1994	304	644	1491	4134	95	482	1845	4917	1056	2238	5178	14362	330	1676	6408	17081	240	509	1177	3264	75	381	1456	3882
1995	304	642	1473	4135	95	479	1831	4929	1056	2229	5118	14365	330	1665	6361	17122	240	507	1163	3265	75	378	1446	3891
1996	304	640	1465	4143	95	477	1823	4940	1056	2222	5088	14392	330	1656	6332	17161	240	505	1156	3271	75	376	1439	3900
1997	304	638	1463	4154	95	475	1820	4948	1056	2217	5084	14431	330	1649	6322	17188	240	504	1155	3280	75	375	1437	3906
1998	304	638	1459	4165	95	476	1817	4963	1056	2216	5069	14469	330	1653	6311	17240	240	504	1152	3288	75	376	1434	3918
1999	304	636	1460	4179	95	475	1814	4977	1056	2211	5071	14515	330	1648	6302	17288	240	502	1152	3299	75	375	1432	3929
2000	304	635	1489	4197	95	475	1840	4989	1056	2207	5173	14578	330	1650	6392	17330	240	502	1176	3313	75	375	1453	3939
2001	304	633	1509	4205	95	473	1860	5001	1056	2200	5242	14609	330	1644	6462	17371	240	500	1191	3320	75	374	1469	3948

Table 7B. Disability in dementia (Crude data per 12 months period): gender, age, severity

Validity Internal: moderate
 External: moderate
 Source: See text

Disability in dementia Crude data per 12 months period

Year	No disability								Partly disabled								Complete disability							
	Males				Females				Males				Females				Males				Females			
	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+
1980	708	2385	2505	1372	233	2043	4627	3258	2460	8284	8701	4764	811	7095	16072	11318	559	1883	1978	1083	184	1613	3653	2572
1981	723	2394	2566	1417	239	2054	4771	3392	2511	8315	8913	4921	830	7134	16574	11783	571	1890	2026	1118	189	1621	3767	2678
1982	725	2402	2642	1458	241	2066	4935	3555	2518	8343	9177	5063	836	7175	17143	12347	572	1896	2086	1151	190	1631	3896	2806
1983	729	2401	2711	1499	242	2067	5086	3726	2531	8342	9417	5207	841	7178	17666	12941	575	1896	2140	1183	191	1631	4015	2941
1984	727	2392	2797	1547	243	2061	5247	3906	2527	8310	9717	5372	844	7161	18228	13568	574	1889	2208	1221	192	1627	4143	3084
1985	698	2410	2859	1588	233	2073	5357	4095	2425	8373	9930	5516	811	7200	18608	14226	551	1903	2257	1254	184	1636	4229	3233
1986	674	2419	2925	1651	226	2076	5470	4292	2343	8404	10162	5736	784	7211	19001	14910	532	1910	2309	1304	178	1639	4319	3389
1987	658	2412	2996	1706	220	2068	5586	4515	2287	8378	10408	5927	764	7182	19404	15685	520	1904	2365	1347	174	1632	4410	3565
1988	644	2402	3060	1745	216	2056	5693	4670	2238	8343	10629	6060	751	7144	19774	16223	509	1896	2416	1377	171	1624	4494	3687
1989	630	2395	3139	1819	212	2045	5808	4879	2189	8319	10905	6320	735	7105	20175	16946	498	1891	2478	1436	167	1615	4585	3851
1990	620	2429	3190	1882	209	2091	5874	5074	2154	8437	11083	6536	725	7262	20405	17625	490	1917	2519	1485	165	1651	4638	4006
1991	613	2442	3228	1954	206	2117	5923	5295	2128	8483	11212	6786	716	7355	20576	18393	484	1928	2548	1542	163	1672	4676	4180
1992	608	2435	3266	2032	204	2120	5980	5518	2112	8458	11344	7059	710	7363	20772	19167	480	1922	2578	1604	161	1673	4721	4356
1993	599	2436	3287	2090	200	2124	5989	5706	2079	8462	11419	7261	695	7378	20803	19821	473	1923	2595	1650	158	1677	4728	4505
1994	596	2427	3310	2208	198	2125	6010	5978	2069	8432	11496	7670	689	7382	20877	20766	470	1916	2613	1743	157	1678	4745	4720
1995	594	2363	3374	2296	196	2063	6123	6205	2064	8210	11720	7974	681	7165	21270	21555	469	1866	2664	1812	155	1628	4834	4899
1996	598	2311	3428	2371	196	2008	6203	6394	2078	8027	11907	8235	682	6974	21547	22212	472	1824	2706	1872	155	1585	4897	5048
1997	606	2277	3458	2453	197	1968	6226	6616	2105	7908	12013	8520	685	6836	21626	22982	478	1797	2730	1936	156	1554	4915	5223
1998	625	2238	3482	2527	202	1936	6237	6820	2170	7774	12095	8777	701	6724	21667	23690	493	1767	2749	1995	159	1528	4924	5384
1999	648	2207	3500	2593	207	1900	6234	6963	2252	7668	12157	9009	720	6599	21654	24188	512	1743	2763	2047	164	1500	4921	5497
2000	667	2193	3597	2643	212	1877	6331	7084	2317	7617	12496	9180	736	6521	21992	24607	527	1731	2840	2086	167	1482	4998	5593
2001	689	2190	3656	2703	217	1859	6388	7174	2392	7608	12699	9388	754	6458	22190	24920	544	1729	2886	2134	171	1468	5043	5664

Table 7C. Disability in dementia (Crude data per 12 months period): gender, severity

Validity Internal: moderate
 External: moderate
 Source: See text

<i>Year</i>	Disability in dementia (Crude data per 12 months period)									
	No disability		Partial disability		Complete disability		No	Partial	Complete	All
	males	females	males	females	males	females	disability	disability	disability	
1980	6969	10161	24209	35296	5502	8022	17130	59505	13524	90159
1981	7099	10456	24660	36322	5605	8255	17555	60982	13860	92397
1982	7226	10796	25101	37502	5705	8523	18022	62603	14228	94853
1983	7340	11120	25497	38626	5795	8779	18460	64123	14573	97156
1984	7463	11458	25926	39800	5892	9046	18921	65726	14938	99585
1985	7555	11758	26244	40845	5965	9283	19314	67089	15248	101650
1986	7670	12064	26644	41907	6056	9524	19734	68551	15580	103865
1987	7773	12389	27000	43036	6136	9781	20162	70035	15917	106114
1988	7851	12636	27271	43892	6198	9975	20486	71163	16173	107823
1989	7984	12944	27733	44962	6303	10219	20927	72695	16522	110144
1990	8121	13247	28210	46017	6411	10459	21368	74227	16870	112465
1991	8236	13542	28609	47040	6502	10691	21778	75648	17193	114619
1992	8341	13822	28973	48013	6585	10912	22163	76986	17497	116645
1993	8412	14019	29221	48697	6641	11068	22431	77918	17709	118058
1994	8541	14312	29668	49715	6743	11299	22853	79383	18042	120278
1995	8627	14587	29968	50670	6811	11516	23214	80638	18327	122179
1996	8707	14801	30247	51415	6874	11685	23509	81662	18559	123730
1997	8794	15007	30546	52129	6942	11847	23800	82675	18790	125265
1998	8871	15195	30815	52781	7003	11996	24065	83596	18999	126661
1999	8949	15304	31086	53161	7065	12082	24253	84247	19147	127647
2000	9100	15504	31610	53855	7184	12240	24604	85465	19424	129493
2001	9237	15638	32088	54321	7293	12346	24875	86409	19638	130923

Table 8A. Ambulatory care. All demented.

Validity Internal: moderate
 External: moderate-poor
 Source: See text

Year	Any kind of visit						Specialist					
	General practitioner			Specialist			General practitioner			Specialist		
	Male 65-74	Male 75-84	85+	Female 65-74	Female 75-84	85+	Male 65-74	Male 75-84	85+	Female 65-74	Female 75-84	85+
1980	43930	52735	21656	21501	97406	51444	37654	46143	21656	43001	85230	51444
1981	44095	54017	22369	21620	100450	53561	37795	47265	22369	43239	87894	53561
1982	44242	55620	23013	21743	103898	56125	37921	48667	23013	43486	90911	56125
1983	44236	57072	23670	21753	107067	58824	37917	49938	23670	43506	93684	58824
1984	44068	58889	24419	21700	110470	61673	37773	51528	24419	43399	96661	61673
1985	44403	60180	25073	21818	112777	64664	38060	52657	25073	43636	98680	64664
1986	44566	61586	26073	21853	115160	67773	38200	53888	26073	43705	100765	67773
1987	44430	63077	26940	21765	117601	71297	38082	55192	26940	43529	102901	71297
1988	44245	64420	27547	21647	119844	73742	37925	56367	27547	43294	104863	73742
1989	44114	66093	28727	21530	122273	77029	37812	57831	28727	43060	106989	77029
1990	44741	67168	29709	22007	123668	80111	38349	58772	29709	44015	108210	80111
1991	44983	67950	30845	22287	124704	83603	38557	59457	30845	44574	109116	83603
1992	44852	68749	32088	22312	125894	87125	38445	60156	32088	44625	110157	87125
1993	44873	69209	33004	22358	126077	90096	38462	60558	33004	44717	110318	90096
1994	44717	69675	34866	22370	126530	94393	38329	60966	34866	44739	110714	94393
1995	43536	71031	36246	21712	128908	97978	37317	62152	36246	43424	112794	97978
1996	42569	72161	37433	21134	130587	100964	36488	63141	37433	42268	114263	100964
1997	41937	72806	38726	20716	131067	104464	35946	63706	38726	41431	114683	104464
1998	41225	73301	39895	20376	131314	107681	35336	64138	39895	40752	114900	107681
1999	40664	73680	40948	19997	131237	109947	34855	64470	40948	39994	114833	109947
2000	40391	75731	41729	19759	133283	111850	34621	66265	41729	39519	116623	111850
2001	40348	76962	42674	19568	134482	113273	34584	67342	42674	39137	117672	113273

Table 8B Ambulatory care. Demented in ordinary living.

Validity Internal: moderate
 External: Moderate-poor
 Source: See text

Year	Any kind of visit											
	General practitioner						Specialist					
	Male			Female			Male			Female		
	65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+
1980	22090	29004	12705	14190	42859	30181	16568	23204	15881	23651	42859	22636
1981	22173	29709	13123	14269	44198	31422	16630	23767	16404	23782	44198	23567
1982	22247	30591	13501	14350	45715	32927	16685	24473	16876	23917	45715	24695
1983	22245	31390	13886	14357	47110	34510	16683	25112	17358	23928	47110	25883
1984	22160	32389	14326	14322	48607	36182	16620	25911	17907	23870	48607	27136
1985	22329	33099	14709	14400	49622	37936	16746	26479	18387	24000	49622	28452
1986	22411	33872	15296	14423	50670	39760	16808	27098	19120	24038	50670	29820
1987	22342	34692	15805	14365	51745	41827	16756	27754	19756	23941	51745	31370
1988	22249	35431	16161	14287	52731	43262	16687	28345	20201	23812	52731	32447
1989	22183	36351	16853	14210	53800	45190	16637	29081	21066	23683	53800	33893
1990	22498	36942	17429	14525	54414	46999	16874	29554	21786	24208	54414	35249
1991	22620	37373	18096	14709	54870	49047	16965	29898	22620	24516	54870	36785
1992	22554	37812	18825	14726	55393	51113	16916	30250	23531	24544	55393	38335
1993	22565	38065	19362	14757	55474	52856	16923	30452	24203	24594	55474	39642
1994	22486	38321	20454	14764	55673	55377	16865	30657	25568	24607	55673	41533
1995	21892	39067	21264	14330	56719	57480	16419	31253	26580	23883	56719	43110
1996	21406	39689	21961	13948	57458	59232	16055	31751	27451	23247	57458	44424
1997	21088	40043	22719	13672	57669	61285	15816	32035	28399	22787	57669	45964
1998	20730	40315	23405	13448	57778	63173	15548	32252	29256	22413	57778	47379
1999	20448	40524	24023	13198	57744	64502	15336	32419	30028	21997	57744	48377
2000	20311	41652	24481	13041	58644	65619	15233	33322	30602	21735	58644	49214
2001	20289	42329	25035	12915	59172	66454	15217	33863	31294	21525	59172	49840

Table 9A. Hospital care care: Number of discharges

Validity Internal high
External moderate

Source: See text

Hospital care (discharges)													
Crude data: number during 12-month period													
Year	Age group	Principal diagnosis						Other diagnosis					
		Male			Female			Male			Female		
		65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+	65-74	75-84	85+
1980	ICD8	569	1197	406	683	1854	1083	115	43	5	102	81	19
1981	ICD8	640	1307	528	705	2037	1181	121	55	9	118	86	23
1982	ICD8	656	1451	558	767	2314	1363	144	97	18	108	108	42
1983	ICD8	725	1590	691	733	2572	1641	149	109	15	117	132	62
1984	ICD8	702	1736	676	844	2610	1716	155	110	27	160	186	56
1985	ICD8	858	2030	804	981	3077	1949	188	160	27	196	186	75
1986	ICD8	895	2200	850	1014	3163	2138	152	155	66	211	217	93
1987	ICD9	1164	3245	1255	1147	3950	3027	425	1264	580	390	1862	1471
1988	ICD9	1255	3678	1414	1182	4192	3338	519	1622	727	396	2047	1858
1989	ICD9	1338	3559	1482	1257	4606	3478	617	1798	875	503	2258	2048
1990	ICD9	1254	3786	1576	1209	4798	3580	568	2008	896	562	2316	2067
1991	ICD9	1518	4610	2380	1533	6970	6502	694	2184	1068	545	2861	2811
1992*	ICD9	865	2118	855	781	2760	1892	497	1547	780	501	2344	1991
1993	ICD9	887	2176	847	852	2727	2101	617	1786	951	583	2764	2542
1994	ICD9	715	2037	661	793	2461	1453	617	1867	1055	614	2949	2635
1995	ICD9	610	1967	641	708	2017	1266	623	2033	1073	589	2963	2809
1996	ICD9	615	1716	666	635	2019	1154	584	2082	1184	605	2913	2791
1997	ICD10	786	1889	778	742	2175	1325	780	2332	1151	829	3492	2906
1998	ICD10	691	1759	846	632	2057	1368	740	2635	1429	812	3760	3247
1999	ICD10	638	1703	730	622	2021	1292	812	2700	1403	856	3739	3394
2000	ICD10	619	1583	765	604	1876	1205	901	2753	1512	844	3762	3484
Total		18000	47337	19409	18424	62256	44052	10018	29340	14851	9641	41026	36424

*1992 is the year of the "Ädel reform" (see text)

Table 9B. Hospital care care: Number of discharges

Validity Internal high
External moderate

Source: See text

Hospital care (discharges)				
Crude data: number during 12-month period				
Year	ICD version	Principal diagnosis	Other diagnosis	All
1980	ICD8	5792	365	6157
1981	ICD8	6398	412	6810
1982	ICD8	7109	517	7626
1983	ICD8	7952	584	8536
1984	ICD8	8284	694	8978
1985	ICD8	9699	832	10531
1986	ICD8	10260	894	11154
1987	ICD9	13788	5992	19780
1988	ICD9	15059	7169	22228
1989	ICD9	15720	8099	23819
1990	ICD9	16203	8417	24620
1991	ICD9	23513	10163	33676
1992*	ICD9	9271	7660	16931
1993	ICD9	9590	9243	18833
1994	ICD9	8120	9737	17857
1995	ICD9	7209	10090	17299
1996	ICD9	6805	10159	16964
1997	ICD10	7695	7689	15384
1998	ICD10	7353	7402	14755
1999	ICD10	7006	7180	14186
2000	ICD10	6652	6934	13586
Total		209478	120232	329710

*1992 is the year of the "Ädel reform" (see text)

Table 9C. Hospital care care: Mean length of stay

Validity Internal high
External moderate

Source: See text

Year	ICD	Hospital care: Mean length of stay				Other diagnosis			
		Principal diagnosis	Principal diagnosis		Other diagnosis		Mean	Median	25th percentile
		Mean	Median	25th percentile	75th percentile	Mean	Median	25th percentile	75th percentile
1980	ICD8	330	62	21	328	306	42	12	235
1981	ICD8	321	67	20	336	316	46	13	255
1982	ICD8	308	60	18	310	303	40	13	247
1983	ICD8	306	59	18	304	308	41	12	249
1984	ICD8	267	47	16	256	292	37	12	243
1985	ICD8	262	40	15	215	286	36	13	267
1986	ICD8	239	33	14	183	277	33	13	241
1987	ICD9	249	30	14	201	244	28	12	151
1988	ICD9	244	28	13	179	212	23	11	119
1989	ICD9	229	23	11	150	190	22	10	101
1990	ICD9	231	22	11	144	193	21	9	91
1991	ICD9	396	64	15	494	201	20	8	110
1992*	ICD9	135	22	10	58	57	13	5	29
1993	ICD9	158	23	9	60	48	11	5	25
1994	ICD9	61	17	6	34	24	9	5	20
1995	ICD9	54	16	7	32	24	8	4	17
1996	ICD9	41	16	7	31	18	9	4	18
1997	ICD10	27	14	7	28	13	8	4	16
1998	ICD10	26	15	7	28	14	8	4	16
1999	ICD10	22	13	6	26	14	8	4	17
2000	ICD10	21	13	6	27	14	8	4	17

*1992 is the year of the “Ädel reform” (see text)

Table 10. Drug treatment with choline esterase inhibitors

Validity (1997-2001) Internal high
External moderate
Source: Apotelsbolaget AB

	Anticholinesterase use: national		Anticholinesterase use: patients		
	Number of DDDs during 12-month period*	DDD's per 1000 and day	Mild	Moderate	Severe
1980	Not approved/no statistics available				Not approved for severe dementia
1981	Not approved/no statistics available				Not approved for severe dementia
1982	Not approved/no statistics available				Not approved for severe dementia
1983	Not approved/no statistics available				Not approved for severe dementia
1984	Not approved/no statistics available				Not approved for severe dementia
1985	Not approved/no statistics available				Not approved for severe dementia
1986	Not approved/no statistics available				Not approved for severe dementia
1987	Not approved/no statistics available				Not approved for severe dementia
1988	Not approved/no statistics available				Not approved for severe dementia
1989	Not approved/no statistics available				Not approved for severe dementia
1990	Not approved/no statistics available				Not approved for severe dementia
1991	Not approved/no statistics available				Not approved for severe dementia
1992	Not approved/no statistics available				Not approved for severe dementia
1993	Not approved/no statistics available				Not approved for severe dementia
1994	Not approved/no statistics available				Not approved for severe dementia
1995	Not approved/no statistics available				Not approved for severe dementia
1996	Not approved/no statistics available				Not approved for severe dementia
1997	548 411	0,17	No separation available		Not approved for severe dementia
1998	1 646 516	0,52	No separation available		Not approved for severe dementia
1999	2 713 476	0,85	No separation available		Not approved for severe dementia
2000	3 826 406	1,2	No separation available		Not approved for severe dementia
2001	5 039 272	1,57	No separation available		Not approved for severe dementia

Table 11 a. Formal home care to demented persons.

Validity Internal moderate-poor
External moderate-poor

Source: See text

Year	Dementia population in ordinary living ("at home")							Home care: number of hours					
	Number of demented during 12-month period			Mean hours per week of all demented in ordinary living				Male			Female		
	65-74	75-84	85+	65-74	75-84	85+	all	65-74	75-84	85+	65-74	75-84	85+
1980	5523	5801	3176	4730	10715	7545	37490	11045	11602	6352	9460	21429	15090
1981	5543	5942	3281	4756	11049	7856	38427	11087	11884	6562	9513	22099	15711
1982	5562	6118	3375	4783	11429	8232	39499	11124	12236	6751	9567	22858	16463
1983	5561	6278	3472	4786	11777	8628	40501	11122	12556	6943	9571	23555	17255
1984	5540	6478	3581	4774	12152	9045	41570	11080	12956	7163	9548	24303	18091
1985	5582	6620	3677	4800	12405	9484	42569	11164	13240	7355	9600	24811	18968
1986	5603	6774	3824	4808	12668	9940	43616	11205	13549	7648	9615	25335	19880
1987	5585	6938	3951	4788	12936	10457	44656	11171	13877	7902	9576	25872	20914
1988	5562	7086	4040	4762	13183	10816	45449	11125	14172	8080	9525	26366	21631
1989	5546	7270	4213	4737	13450	11298	46514	11092	14540	8427	9473	26900	22595
1990	5625	7388	4357	4842	13603	11750	47565	11249	14777	8715	9683	27207	23499
1991	5655	7475	4524	4903	13717	12262	48536	11310	14949	9048	9806	27435	24524
1992*	5639	7562	4706	4909	13848	12778	49443	11277	15125	9412	9817	27697	25557
1993	5641	7613	4841	4919	13869	13214	50096	11282	15226	9681	9838	27737	26428
1994	5622	7664	5114	4921	13918	13844	51083	11243	15329	10227	9843	27837	27689
1995	5473	7813	5316	4777	14180	14370	51929	10946	15627	10632	9553	28360	28740
1996	5352	7938	5490	4649	14365	14808	52602	10703	15875	10980	9299	28729	29616
1997	5272	8009	5680	4557	14417	15321	53257	10544	16017	11360	9115	28835	30643
1998	5183	8063	5851	4483	14445	15793	53817	10365	16126	11702	8965	28889	31586
1999	5112	8105	6006	4399	14436	16126	54183	10224	16210	12011	8799	28872	32251
2000	5078	8330	6120	4347	14661	16405	54941	10155	16661	12241	8694	29322	32809
2001	5072	8466	6259	4305	14793	16613	55508	10145	16932	12518	8610	29586	33227

Table 11 b. Day care to demented persons.

Validity Internal moderate-poor
External moderate-poor

Source: See text

Day Care						
Mean number of visits per week of home care dementia population						
Year	Male			Female		
	65-74	75-84	85+	65-74	75-84	85+
1980	1381	1450	794	1183	2679	1886
1981	1386	1485	820	1189	2762	1964
1982	1390	1530	844	1196	2857	2058
1983	1390	1569	868	1196	2944	2157
1984	1385	1619	895	1193	3038	2261
1985	1396	1655	919	1200	3101	2371
1986	1401	1694	956	1202	3167	2485
1987	1396	1735	988	1197	3234	2614
1988	1391	1772	1010	1191	3296	2704
1989	1386	1818	1053	1184	3363	2824
1990	1406	1847	1089	1210	3401	2937
1991	1414	1869	1131	1226	3429	3065
1992	1410	1891	1177	1227	3462	3195
1993	1410	1903	1210	1230	3467	3304
1994	1405	1916	1278	1230	3480	3461
1995	1368	1953	1329	1194	3545	3593
1996	1338	1984	1373	1162	3591	3702
1997	1318	2002	1420	1139	3604	3830
1998	1296	2016	1463	1121	3611	3948
1999	1278	2026	1501	1100	3609	4031
2000	1269	2083	1530	1087	3665	4101
2001	1268	2116	1565	1076	3698	4153

Table 12. Staff ratio in long-term residential care

Validity Internal moderate
 External moderate

Source: See text

	Number of staff per patient		Number of patients per staff	
	Nursing homes	Specialised units	Nursing homes	Specialised units
1980	0,66*		1,52	
1981				
1982				
1983				
1984				
1985				
1986				
1987				
1988				
1989				
1990				
1991				
1992				
1993	1,19*		0,84	
1994				
1995				
1996	1,17*		0,85	
1997				
1998	1,05*		0,95	
1999				
2000				
2001	0,89	1,01	1,12	0,99
	*=local figures		*=local figures	

Table 13. Number of demented receiving long term institutional/residential care as compared with all elderly receiving long term institutional care.

Validity Internal moderate
External moderate

Source: See text

	Dementia patients receiving long-term institutional care			All elderly receiving long-term institutional care		
	Crude data (number of persons)			Crude data (number of persons)		
	<i>Ownership</i>					
	Public	Private	all	Public	Private	all
1980						
1981						
1982						
1983						
1984						
1985						
1986						
1987						
1988						
1989						
1990						
1991						
	THE ÄDEL REFORM (see text)					
1992						
1993	67334	3844	71178	106879	6101	112980
1994	70055	5354	75409	111198	8498	119696
1995	69844	6322	76165	110863	10034	120897
1996	67576	6929	74505	107263	10998	118262
1997	68861	7822	76683	109303	12415	121719
1998	67461	7329	74790	107081	11634	118715
1999	66136	7104	73240	104977	11277	116254
2000	67557	8865	76422	107234	14071	121305
2001	65539	9192	74731	104031	14590	118621

Table 14A. Informal care. Description of caregivers.

Validity Internal poor
 External moderate
 Source: See text

Relationship between caregiver and dementia patient

	Number of caregivers							
	Males	Females	Males			Females		
			Spouse	Child/child-in-law	Other	Spouse	Child/child-in-law	Other
1980	14246	23244	12964	1282	0	16735	6043	465
1981	14602	23825	13288	1314	0	17154	6194	476
1982	15010	24489	13659	1351	0	17632	6367	490
1983	15390	25111	14005	1385	0	18080	6529	502
1984	15797	25774	14375	1422	0	18557	6701	515
1985	16176	26393	14720	1456	0	19003	6862	528
1986	16574	27042	15083	1492	0	19470	7031	541
1987	16969	27687	15442	1527	0	19935	7199	554
1988	17271	28179	15716	1554	0	20289	7326	564
1989	17675	28838	16084	1591	0	20764	7498	577
1990	18075	29490	16448	1627	0	21233	7667	590
1991	18444	30092	16784	1660	0	21666	7824	602
1992	18788	30654	17097	1691	0	22071	7970	613
1993	19037	31060	17323	1713	0	22363	8075	621
1994	19412	31672	17665	1747	0	22804	8235	633
1995	19733	32196	17957	1776	0	23181	8371	644
1996	19989	32613	18190	1799	0	23481	8479	652
1997	20238	33019	18416	1821	0	23774	8585	660
1998	20451	33367	18610	1841	0	24024	8675	667
1999	20590	33594	18737	1853	0	24188	8734	672
2000	20878	34064	18999	1879	0	24526	8857	681
2001	21093	34415	19195	1898	0	24779	8948	688

Table 14B. Informal care. Amount of informal care.

Validity Internal poor
 External moderate
 Source: See text

	Amount of care			
	Mean hours per week per caregiver		Total number of hours per week All caregivers	
	ADL+IADL	ADL+IADL+Supervision	ADL+IADL	ADL+IADL+Supervision
1980	37	75	1387116	2811722
1981	37	75	1421814	2882055
1982	37	75	1461467	2962433
1983	37	75	1498543	3037586
1984	37	75	1538100	3117771
1985	37	75	1575048	3192665
1986	37	75	1613802	3271220
1987	37	75	1652283	3349222
1988	37	75	1681626	3408702
1989	37	75	1721003	3488519
1990	37	75	1759909	3567383
1991	37	75	1795830	3640197
1992	37	75	1829376	3708195
1993	37	75	1853557	3757210
1994	37	75	1890083	3831250
1995	37	75	1921378	3894685
1996	37	75	1946258	3945117
1997	37	75	1970499	3994255
1998	37	75	1991238	4036294
1999	37	75	2004788	4063760
2000	37	75	2032829	4120600
2001	37	75	2053814	4163136

Table 15. Time to long term institutional care. Data forthcoming.

Validity Internal High
 External High
 Source: See text

Time to admission to LTC institution							
Mean number of months							
	Sex	Males			Females		
	Age group	65-74	75-84	85+	65-74	75-84	85+
1980	Data forthcoming						
1981	Data forthcoming						
1982	Data forthcoming						
1983	Data forthcoming						
1984	Data forthcoming						
1985	Data forthcoming						
1986	Data forthcoming						
1987	Data forthcoming						
1988	Data forthcoming						
1989	Data forthcoming						
1990	Data forthcoming						
1991	Data forthcoming						
1992	Data forthcoming						
1993	Data forthcoming						
1994	Data forthcoming						
1995	Data forthcoming						
1996	Data forthcoming						
1997	Data forthcoming						
1998	Data forthcoming						
1999	Data forthcoming						
2000	Data forthcoming						
2001	Data forthcoming						

Table 16. Expenditures on choline-esterase inhibitors.

Validity (1997-2001) Internal High
 External High
 Source: Apoteksbolaget

	Sales (SEK)
1980	Not approved/no statistics available
1981	Not approved/no statistics available
1982	Not approved/no statistics available
1983	Not approved/no statistics available
1984	Not approved/no statistics available
1985	Not approved/no statistics available
1986	Not approved/no statistics available
1987	Not approved/no statistics available
1988	Not approved/no statistics available
1989	Not approved/no statistics available
1990	Not approved/no statistics available
1991	Not approved/no statistics available
1992	Not approved/no statistics available
1993	Not approved/no statistics available
1994	Not approved/no statistics available
1995	Not approved/no statistics available
1996	Not approved/no statistics available
1997	23 024 380
1998	71 163 661
1999	114 261 975
2000	149 983 284
2001	192 418 448