

# Senile Dementia of the Alzheimer Type in the Lundby Study

## I. A Prospective, Epidemiological Study of Incidence and Risk During the 15 Years 1957–1972\*

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Received February 11, 1991

**Summary.** In spite of the great impact of senile dementia of the Alzheimer type (SDAT) on society, far too little is known about its epidemiology. In this study of a total, normal population from a geographically delimited area in Sweden, Lundby, 2612 persons were examined in 1957 by one psychiatrist (Hagnell). In 1972 the same population was reexamined irrespective of domicile. The incidence and risk of contracting SDAT during the 15 years were calculated. No cases of SDAT were diagnosed before the age of 60 years. The lifetime risk was for men 25.7% and for women 26.2%. When only the very severely impaired were taken into account, the figures were 14.5% in men and 14.6% in women.

**Key words:** Alzheimer – Dementia – Longitudinal – Incidence – Lundby Study

### Introduction

Clinical studies restricted to inpatients do not give a representative picture of mental morbidity in society, reflecting it only in part. In a comprehensive study, Cooper and Bickel (1989) showed how the incidence rate of dementia derived from field studies in each age group greatly exceeded that from case studies. This fact makes epidemiological research on dementia with reference to the total population important not only for the planning of care but also for the study of aetiology. The Lundby Study is well suited in this respect.

\*This study has been supported by the following grants: The Bank of Sweden Tercentenary Foundation No. 71/2; The Swedish Medical Research Council Nos. 3474, 4803, 6008, 6881; The Swedish Ministry of Health and Social Affairs, Delegation for Social Research No. 83/64:1–2.

The study has been performed with approval of the Ethical Committee of the Lund University Faculty of Medicine and with the permission of the Swedish Data Inspection Board.

Within the Lundby project several subpopulations can be chosen for investigation, e.g. those examined at the different cross-section dates or according to various segments of the population, different residence criteria, etc. Having performed two follow-up studies since the original Lundby Study in 1947, we have gained more knowledge in the course of time. The first field study in 1947 was a pioneering work by which we benefited greatly at the further studies in 1957 and 1972, so as to reach a longitudinal, epidemiological perspective.

The epidemiology of age psychosis in the Lundby Study has been approached in a series of publications (Gruenberg et al., 1987; Hagnell et al. 1981; 1983; 1990; Rorsman et al. 1985a, 1985b; 1986). The 1957 cohort, the population sample of the present study, was chosen as being the most suitable for providing incidence rates and possible background factors of senile dementia of the Alzheimer type (SDAT).

### Method

This incidence study covers the 2612 persons who, on 1 July 1957, were on the population register of a geographically delimited area in southern Sweden called Lundby. This area is identical with the one investigated in 1947 by Essen-Möller et al. (1956). The 1957 cohort, the population sample of this study, is unlike the original cohort of 1947 because of emigration (700) and death (253). Of the 1013 newcomers, 340 were children under the age of ten, most of them born to parents belonging to the 1947 cohort (Tables 1 and 2). In 1957, all the probands were examined by one psychiatrist (Hagnell, 1966). For a further description of the 1957 cohort, see Hagnell et al. (1986). In 1972 with the same cross-section date, the same persons were reinvestigated, irrespective of domicile, by the two psychiatrists Hagnell and Öjesjö (Hagnell et al., 1990). They were both trained at the psychiatric clinic of the Lund University Hospital in the same tradition as the 1947 examiners. At the 1972 survey they worked in close cooperation to ensure the continuity of assessment of caseness and diagnostic criteria.

In all the field investigations the non-response figure could be kept very low, at 1–2%. Information was collected through personal examinations by experienced psychiatrists and from supple-

**Table 1.** Survey of the 1957 Lundby cohort on July 1, 1957 ( $n = 2612$ )

Age 1957	Remaining 1947 cohort	Newcomers in 1957	Total male cohort
<i>Men</i>			
0- 9	-	169	169
10-19	147	69	216
20-29	105	65	170
30-39	86	84	170
40-49	138	55	193
50-59	158	43	201
60-69	88	11	99
70-79	63	7	70
80+	39	8	47
0+	824	511	1335
			Total female cohort
<i>Women</i>			
0- 9	-	171	171
10-19	139	70	209
20-29	69	80	149
30-39	75	75	150
40-49	137	52	189
50-59	140	32	172
60-69	113	10	123
70-79	74	8	32
80+	28	4	32
0+	775	502	1277
Total of cohort	1599	1013	2612

mentary sources such as various official registers, hospital case notes, and so-called key informants. For those 416 who died during the 15-year observation period, date and cause of death were available through official channels. For most of the deceased information was collected from relatives and other sources sufficient for an evaluation of their mental health up to the time of their death. In the course of the 15-year investigation period changes occurred in the community, for example urbanization, an improved health service system, safer social conditions, better domestic economy, and thereby better possibilities for a good standard of living and health protection.

The personal examination usually took place at the proband's home, where the psychiatrist wrote down the proband's history about his/her mental and physical health, social relations, professional career, and socio-economic background. Then followed a semi-structural interview based on a file of items with the aim of describing the proband's behaviour, personality, mental traits, etc. The subject usually regarded the examination as finished when the examiner put his paper and pencil in his pocket. A relaxed chat afterwards very often resulted in important additional information. All cases were then evaluated by either of the two psychiatrists, and later a joint evaluation was made. In this, all information, primary and additional was used.

The Lundby diagnostic criteria of 'age psychosis' have remained the same throughout the study and were presented in detail in the 1957 and 1972 reports of the Lundby Study (Hagnell, 1966; Hagnell et al., 1990). In the 1980s, our cases of age psychosis were reevaluated as either senile or multi-infarct dementia according to Roth's (1955) organic brain syndrome (OBS). In order to adjust to current terminology, we now use SDAT instead of the earlier term 'senile dementia'. Compared with modern criteria our

**Table 2.** Surviving persons of the 1957 Lundby cohort interviewed or sufficiently known in 1972, distributed by sex and age ( $n = 2612$ )

Age 1957	Alive 1972	Personally examined 1972	With enough information 1972	
	<i>n</i>	<i>n</i>	%	%
<i>Men</i>				
0-49	627	619	98.7	99.8
50-59	172	172	100.0	100.0
60-69	191	191	100.0	100.0
70-79	87	83	95.4	98.9
80+	26	20	76.9	100.0
0+	1103	1085	98.4	99.8
<i>Women</i>				
0-49	608	603	99.2	99.5
50-59	144	144	100.0	100.0
60-69	177	177	100.0	100.0
70-79	115	113	98.3	100.0
80+	49	43	87.8	100.0
0+	1093	1080	98.8	99.7
Total of cohort	2196	2165	98.6	99.8

cases of SDAT broadly correspond to the "primary degenerative dementia of the Alzheimer type" of the DSM-III (APA, 1987). No reevaluations according to DSM-III were, however, made.

The often slow and insidious onset of dementia made it difficult for us to decide when the disease began. The first signs, such as cognitive, were mostly reported by those in the immediate environment of the sick person. Those who knew the person well gave important information about changes of personality traits and physical, mental, and social conditions. When in doubt about a person being healthy or sick, we always chose the "healthier" alternative. A few probands with incipient SDAT may in this way have been excluded, but on the other hand we can be sure that the frequencies shown are not exaggerated.

The degree of impairment was rated as severe, medium or mild in accordance with the previous Lundby Study (Hagnell, 1966). It should be emphasized that the 'mild' group does not include borderline cases; rather, even mildly impaired subjects had, beyond doubt, symptoms of such a degree that the evaluating psychiatrist considered their mental condition to be definitely pathological and of clinical significance, requiring therapeutic intervention.

### *What is Meant by a Case of SDAT in the Lundby Study?*

The essential feature is a loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning. The deficit is multifaceted and involves memory, judgement, abstract thought, and a variety of other higher cortical functions. Changes in personality and behaviour may also occur. At the beginning of SDAT, self-centredness, difficulty in grasping ideas, and bluntness of emotionality are common. The general deterioration is insidious and may be minimal or steadily progress towards a vegetative existence. Sometimes productive symptoms like delusions, hallucinations or restlessness are present.

Persons with focal neurological signs and symptoms were always placed in the multi-infarct group, whether the differential diagnosis was hard to state or whether they could be regarded as mixed cases. We are quite aware that focal symptoms may appear even in disorders other than MID, but in epidemiological field studies, clinical examinations are hard to perform.

To illustrate our concept of SDAT two case histories are given here.

### Case 1

As a child she was delicate and cried easily but did well at school. In her younger years, she had attacks of headache with flickering before her eyes and blurred vision, but later on she improved. She always had trouble with her nerves. The death of her parents, whom she had stayed with even as a grown-up, was a great shock to her and she was still mourning them after 30 years. She remained unmarried and lived alone in her own house, occupied with farming, which she enjoyed very much. At the interview in 1957, when she was 76 years old, she was described as a kind and gentle woman, extremely unsecure and 'subvalid' (prone to tension and fatigue), who was living a retired life. She became worried and anxious easily and had various obsessions and compulsions about controlling things, and she never left her home. At the age of 86 she fell and broke both her femurs, but after proper treatment she was able to return home where she was looked after by relatives and private nurses. Most of the time she stayed in bed, having difficulty in walking. Later on she was admitted to a geriatric nursing-home, the situation at home being too hard to manage. On admission, she was mentally well-preserved except for an impaired memory of recent personal experiences and current happenings. Gradually, however, she became more and more absent and had attacks of screaming and aggressive outbursts. In between, she was calm and lucid. She recognized her relatives. In the daytime she was up, sitting in an armchair. She managed to eat by herself but needed help with washing and dressing. She became increasingly absent and blunted.

**Evaluation:** SDAT, medium impairment; corresponding to ICD 290.00 and DSM-III 290.00.

### Case 2

He was always physically healthy except for otitis in his forties. After finishing school, he worked as a farming manager. When his father died, he took over the tenant farm and lived there with his wife and two children. When he was aged 76 years, he retired from his farming, but he kept himself in good physical condition by cycling 50–60 km almost every day. He made a very kind and gentle impression at the examination in 1957; he was then 77 years old. Being delicate and vulnerable, he took things very hard. He was a quiet man with a pyknic constitution, mild and unobtrusive. A couple of years later he showed the first signs of an impaired memory. This resulted, among other things, in him having severe difficulty in driving, and once he accidentally ran into a car. His memory continued to deteriorate and he became increasingly anxious and restless, days as well as nights. His speech became blurred, and he answered only when he was spoken to, and then often without rhyme or reason. He did not recognize his wife or his children, and when eating he could not handle his knife and fork. He was unable to control his bowels and bladder, and his family had to look after him continuously, preventing him from running out and being killed in the traffic. He was admitted to a psychiatric hospital at the age of 82. There he was completely confused concerning time, place, and person, and the only thing he could remember was his parental home. One month after admission he died of cardiosclerosis and pneumonia.

**Evaluation:** SDAT, severe impairment; corresponding to ICD 290.00 and DSM-III 290.00.

Through the 1947 field study and the careful, retrospective follow-up of the population up to the cross-section date of 1 July 1957 we know that all the probands who at that date had SDAT were registered. No proband who was diagnosed as having SDAT later recovered. At the starting point of the present study in 1957, the population thus consisted of two groups: those who did not have

SDAT and those who had. The number of those who were healthy in 1957 but contracted SDAT during the subsequent 15-year period, including those who died, hence gives us the incidence of the illness during the period 1957–1972.

### Statistical Method

The first step in our statistical procedure was to determine, for each person involved, a period of risk. In the absence of any episode of the illness in question before 1 July 1957, the risk period starts on that date; however, if such a previous episode has occurred, no risk period exists at all. Then the period, if any, lasts until 1 July 1972, death, or onset of illness, whichever occurs first. Note that the start of an episode once and for all terminates the risk period (as SDAT must be regarded as a chronic disease). The risk period is then divided into segments, a new segment beginning when the person enters a new 10-year age group. Finally, the results are aggregated over the entire cohort, i.e. for every age group, the lengths of all risk-period segments in that age group are added together. In the same way, the number of first episodes of SDAT is counted for each age group. During both these aggregation procedures the two sexes are treated separately. The statistically interested reader is referred to Rorsman et al. (1990) for further details of the method used.

### Results

The incidence and risk of contracting SDAT for the first time based on data from a total population, the 1957 Lundby cohort, during the 15-year period 1957–1972 are given in Table 3a–c. The cumulative probability for the 15-year period of contracting SDAT up to the age of 90 years (all types of impairment taken together) was very similar for men and women (25.7% and 26.2% respectively). Up to the age of 80 years, however, the risk of contracting the illness was slightly higher for men (8.3%) than for women (6.1%), though this is a difference without statistical significance. No case of presenile dementia was found in this cohort.

### Discussion

Earlier, Hagnell et al. (1983) presented a study of the incidence and risk of contracting SDAT during the same period of time but for the 1947 Lundby cohort. The present investigation of the 1957 cohort showed no essential discrepancies with regard to these figures. The small, not statistically significant, difference between the sexes is in accordance with the results from other incidence studies on SDAT, despite certain methodological diversities (Åkesson, 1967; Nilsson, 1984) (Table 4). Katzman et al. (1989) found, however, in a prospective incidence study of 434 community volunteers, that the two major risk factors of SDAT were age and female sex.

Our rates of SDAT closely resemble those obtained from the incidence study of old people in Mannheim (Cooper and Bickel, 1989), a field study involving direct psychiatric assessments by experienced clinicians. The comparatively high figures in the Gothenburg study (Nilsson, 1984) might, according to the author himself, partly be due to the nature of the population (being urban) and the diagnostic methods relying on few signs with a possible overinclusion of "false" dementias as a consequence.

**Table 3a–c.** The incidence and risk of contracting senile dementia of the Alzheimer type for the first time, based on data from a total population during the 15-year period 1957–1972

Age interval	Observation years under risk	Cases	Rate per year	Probability of disease during age interval	Cumulative probability of disease
<b>a Degree of impairment: Severe</b>					
<b>Men</b>					
0–49	11490.5	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
50–59	3005.3	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
60–69	2213.3	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
70–79	1122.1	5	0.0045 (0.0020)	0.044 (0.019)	0.044 (0.019)
80–89	445.9	5	0.0112 (0.0050)	0.106 (0.045)	0.145 (0.046)
90–99	66.5	0	0.0000 (0.0000)	–	–
100+	0.0	0	0.0000 (0.0000)	–	–
0+	18343.6	10	0.0004 (0.0001)	–	–
<b>Women</b>					
0–49	10848.5	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
50–59	2687.0	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
60–69	2271.0	3	0.0013 (0.0008)	0.013 (0.008)	0.013 (0.008)
70–79	1351.7	4	0.0030 (0.0015)	0.029 (0.014)	0.042 (0.016)
80–89	520.5	6	0.0115 (0.0047)	0.109 (0.042)	0.146 (0.043)
90–99	63.5	1	0.0157 (0.0157)	–	–
100+	2.6	0	0.0000 (0.0000)	–	–
0+	17744.8	14	0.0006 (0.0002)	–	–
<b>b Degree of impairment: Severe + Medium</b>					
<b>Men</b>					
0–49	11490.5	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
50–59	3005.3	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
60–69	2207.3	1	0.0005 (0.0005)	0.005 (0.005)	0.005 (0.005)
70–79	1100.9	9	0.0082 (0.0027)	0.078 (0.025)	0.083 (0.025)
80–89	430.8	8	0.0186 (0.0066)	0.169 (0.055)	0.238 (0.054)
90–99	65.8	0	0.0000 (0.0000)	–	–
100+	0.0	0	0.0000 (0.0000)	–	–
0+	18300.6	18	0.0008 (0.0002)	–	–
<b>Women</b>					
0–49	10848.5	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
50–59	2687.0	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
60–69	2269.6	4	0.0018 (0.0009)	0.017 (0.009)	0.017 (0.009)
70–79	1337.2	5	0.0037 (0.0017)	0.037 (0.016)	0.054 (0.018)
80–89	511.0	9	0.0176 (0.0059)	0.161 (0.049)	0.206 (0.049)
90–99	62.3	1	0.0161 (0.0161)	–	–
100+	2.6	0	0.0000 (0.0000)	–	–
0+	17718.2	19	0.0009 (0.0002)	–	–
<b>c Degree of impairment: Severe + Medium + Mild</b>					
<b>Men</b>					
0–49	11490.5	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
50–59	3005.3	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
60–69	2207.3	1	0.0005 (0.0005)	0.005 (0.005)	0.005 (0.005)
70–79	1100.9	9	0.0082 (0.0027)	0.078 (0.025)	0.083 (0.025)
80–89	427.7	9	0.0210 (0.0070)	0.190 (0.057)	0.257 (0.056)
90–99	64.1	0	0.0000 (0.0000)	–	–
100+	0.0	0	0.0000 (0.0000)	–	–
0+	18295.8	19	0.0009 (0.0002)	–	–

**Table 3a-c** (continued)

Age interval	Observation years under risk	Cases	Rate per year	Probability of disease during age interval	Cumulative probability of disease
<b>Women</b>					
0-49	10848.5	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
50-59	2687.0	0	0.0000 (0.0000)	0.000 (0.000)	0.000 (0.000)
60-69	2269.6	4	0.0018 (0.0009)	0.017 (0.009)	0.017 (0.009)
70-79	1336.9	6	0.0045 (0.0018)	0.044 (0.018)	0.061 (0.019)
80-89	497.9	12	0.0241 (0.0070)	0.214 (0.055)	0.262 (0.054)
90-99	62.1	1	0.0161 (0.0161)	-	-
100+	2.6	0	0.0000 (0.0000)	-	-
0+	17704.6	23	0.0011 (0.0002)	-	-

**Table 4.** Survey of some incidence studies on senile dementia of the Alzheimer type

Author and country	Type of survey and population	Methods	Degree of impairment and age of onset	Incidence rate per 1000
Åkesson, Swedish Isles, 1964-67	Case study, rural	PE + R	Severe	M 2.4
			60 +	F 5.2
Hagnell, Lundby, Sweden, 1957-72	Field study, rural/urban	PE + R	Medium + Severe	M 10.6
			70 +	F 7.9
Nilsson, Gothenburg, Sweden, 1971-81	Field study, urban	PE + R	Severe	M 4.4
			70-75	F 3.0
			75-79	M 17.6
				F 11.0
Cooper and Bickel, Mannheim, Germany, 1978-86	Field study, urban	PE + R	Moderate + Severe 65 +	M + F 9.4

PE = Psychiatric examination; R = Records (case/official); M = Male; F = Female

This study only included "severe" cases of SDAT, mostly inpatients with a high degree of institutionalization. Åkesson's low rates derive from an accurately performed case study (1967) on a quite different material. Very strict criteria were applied to a population that was rural, and most of the cases, all severely impaired, were living at home at the census date.

Diagnostic problems, such as distinguishing primary dementias from other disorders play an important role in the explanation of the divergent outcome in various studies. We cannot exclude the possibility of some incipient cases of SDAT being "hidden" in the group of 'age neurosis' in our study. On the other hand, we feel that those elderly depressives who appeared as demented were placed with a high degree of accuracy within the group of 'depression'. Of course, other forms of age dementia exist but are unusual compared with the large groups, MID and SDAT, and not easily recognized in epidemiological studies. Differences in the use of degrees of impairment present another problem. For instance, if the "mild" cases are not included, there is a tendency to report higher rates of "moderate" and "severe" categories (Jorm et al., 1988; Brayne and Calloway, 1989).

Even if DSM-III had existed at the time for our field study, we would not have found it suitable for our pur-

pose. At a next follow-up a new classification system will probably be current. These changes in diagnostic classification systems present serious complications for longitudinal population studies. Still, the standardisation and validation of psychiatric instruments continue to be of great value for the epidemiological research on dementias, together with the evaluation of the status and case history by a trained psychiatrist.

SDAT presents an enormous problem for our society, from both a medical-humanitarian and an economic point of view. The EURODEM group is now, among others, conducting a large-scale compilation of European epidemiological studies on dementias of the elderly. Until effective treatment is available, it is important to refine the diagnostics, in order to trace early cases, perform clinical evaluations, and, if possible, by support and social training to delay further progress of the disease. Also, for the purpose of prevention, it is important to be able to identify the persons who run an increased risk of developing the disease. In a subsequent paper, the 1957 Lundby cohort is studied concerning predictive factors of importance for developing SDAT or for staying healthy in this respect (Hagnell et al., 1991).

*Acknowledgements.* We sincerely thank J. Lanke for the statistical work, and R. G. Dewsnap for revising the manuscript.

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