Prognosis of patients with dementia after admission to a Dutch Nursing Home

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Prognose bij patiënten met dementie na opname in het verpleeghuis

PROEFSCHRIFT

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Promotoren:	Prof. Dr JDF Habbema
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Overige leden:	Prof. Dr A Hofman
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Chapter 1 - 7 and the Appendix consist of versions of the following papers:

Chapter 1	van Dijk PTM, Dippel DWJ, Habbema JDF. Survival of patients with dementia. J Am Geriatr Soc 1991;39:603-610.
Chapter 2	van Dijk PTM, van de Sande HJ, Dippel DWJ, Habbema JDF. The nature of excess mortality in nursing home patients with dementia. J Gerontol: Med Sci 1992;47:M28-34.
Chapter 3	van Dijk PTM, Dippel DWJ, Habbema JDF. A behavior rating scale as a predictor for survival of demented nursing home patients. Arch Gerontol Geriatr 1994;18:101-113.
Chapter 4	van Dijk PTM, Dippel DWJ, van der Meulen JHP, Habbema JDF. Comorbidity and its effect on mortality in nursing home patients with dementia. Submitted for publication.
Chapter 5	van Dijk PTM, van der Meulen JHP, Dippel DWJ, Habbema JDF. A model for prediction of survival chances in nursing home patients with dementia. Submitted for publication.
Chapter 6	van Dijk PTM, Dippel DWJ, van der Meulen JHP, Habbema JDF. The course of dependency in patients with dementia in a skilled nursing facility. Submitted for publication.
Chapter 7	van Dijk PTM, Meulenberg OGRM, van de Sande HJ, Habbema JDF. Falls in dementia patients. The Gerontologist 1993;33:200-204.
Appendix	van Dijk PTM, Duivenvoorden HJ, Habbema JDF. De subschalen van de BOP in de psychogeriatrie. Tijdschr Gerontol Geriatr 1991;22:181-186.
	Meulenberg OGRM, van Dijk PTM, van de Sande HJ, Habbema JDF. Vallen en opstaan in een psychogeriatrisch verpleeghuis. Twee jaar Meldingsformulier Incidenten Bewonerszorg. Tijdschr Gerontol Geriatr 1991;22:216-220.

Contents

Introduction

Modern medicine is focused on diagnosing and treating diseases in order to cure a patient from his disease, to relieve his symptoms, and, in most cases, to increase his life-expectancy. Alas, until now there is no cure for most patients who have dementia. Furthermore, if they suffer from comorbid illness, it is often impossible for them to understand the implications of diagnostic and therapeutic strategies, and the wish of the patient to want or not to want to undergo medical procedures can often not be deduced. Two examples illustrate that these problems can also occur in a Dutch Nursing Home.

> Patient A is man of 80 years old. He was suffering from dementia since about four years, and was admitted to a Dutch Nursing Home six months ago. He had lost his ability to walk, and he needed some help in activities of daily life. Since four months he regularly complained about a vague pain in the abdominal region. He lost his appetite, and his weight decreased from 64 to 56 kilogram. Stool tests showed blood loss. Blood-haemoglobin decreased from 7.2 to 6.2 mmol/liter in this period.

> Patient B is a women of 85 years old. She was suffering from dementia since about six years. Nevertheless, she was only mildly demented. Physical examination at admission to the Dutch Nursing Home revealed that her impaired vision was probably mainly caused by senile cataract.

In both patients the Dutch Nursing Home physician has to decide whether he will send them to a specialist for further diagnostic research, or for a senile cataract extraction. Does Patient A have a malignancy in the digestive tract, and is abdominal surgery necessary? Will the patient get an anus praeternaturalis, and is he able to cope with it? What will the prognosis be if no surgery is performed ? Will patient B profit from a cataract extraction, and for how long? How will she react to the hospital admission and to the anaesthesia?
A decision analysis can be helpful in structuring the problem and determining which strategy is in the best interest of the particular patient. The prognosis in terms of life expectancy plays an important role in this matter. Unfortunately the available literature provides only little information about the prognosis of dementia patients, especially if one wants to take patient characteristics such as gender, age, severity of dementia, and comorbidity into account. Therefore we started a study of survival and prognostic factors for survival in dementia patients. This thesis describes the results of this study. They will be of help for the Dutch Nursing Home physician in decision-making for the individual patient where the life expectancy plays an

important role. They may also be relevant for getting more insight in the natural course of dementia process. Health care planners can use our results in predictions of the effects of changes in admission policy, and the capacity needed for dementia patients.
Before the results are described, a short definition of dementia and its natural course, its etiology, and its epidemiology will be given. After that the Dutch Nursing Home Stadzicht (the study-site) will be described in relation to the other Dutch Nursing Homes.

Dementia
Dementia is one of the major health problems in the elderly. This syndrome, which can be caused by several diseases, has a variable symptomatology and can comprise memory disturbances, loss of cognitive functions, personality changes, and impaired judgment. Especially in the early stages it can be difficult to discriminate between dementia, depression and normal aging. In order to come to more uniformity in establishing the diagnosis, to diminish the number of incorrect diagnoses of dementia, and for scientific purposes, criteria for dementia have been developed. Well known are the DSM-III(-R) - criteria [1]. In the Netherlands, a Consensus Meeting has been held in November 1988 to come to uniform criteria, to reduce uncertainty about the definition of dementia and related diseases, and to assess the value of several diagnostic possibilities [2]. These criteria are largely based on the DSM-III-R. Criteria are also described by the Dutch general practitioners [3].
There are several types of dementia, of which Senile Dementia of the Alzheimer Type is the most prevalent: in western society relative frequencies between 40% and 85% are reported for SDAT [4]. About 20% to 40% suffer from multi-infarct dementia. The clinical differentiation between these 2 causes of dementia is often very difficult, and a combination of these 2 diseases is also possible.
The pathogenesis of Alzheimer's disease is largely unknown, but is probably related to an error in the metabolism of β-amyloid-precursor-protein in the brain, leading to an overdose of a smaller protein, β-A4. This protein can aggregate into fibrillary amyloid, and henceforth to neurofibrillary tangles [5]. Insight in the pathogenesis may lead to therapeutic possibilities. Multi-infarct dementia is caused by multiple infarcts in the brain, due to thrombosis or embolism. Progression of the underlying atheromatous disease is often accelerated by hypertension.

Other, much less prevalent causes of dementia are normal pressure hydrocephalus, vitamin B_{12} deficiency, parkinsonism, syphilis, subdural haematoma, prescription drugs, thyroid disease, and so on [6]. An adequate identification and treatment of reversible causes can lead to improvement of symptoms. Alas often these dementias are only partially or temporarily reversible [6,7], and concern only a minority of cases. It seems that reversible causes show relatively more often symptomatology of a subcortical dementia (such as loss of initiative, attention and concentration, dysarthria, gait disturbance), whereas Alzheimer's disease more often shows the symptomatology of a cortical dementia (such as disturbance in spatial orientation, apraxia, and aphasia). Paying attention to this difference in symptomatology might be useful [8], although this has not yet been proven in prospective studies.
In the early stages the diagnosis dementia is not always recognized, especially when memory disturbances are subtle or emerge gradually. It can be very difficult to distinguish between a dementia and a depression [9]. Initially, problems may only rise when difficult and complicated tasks have to be performed at home or at work. Personality changes can emerge, and the patient may loose his ability to plan his activities in a logical way. If other cognitive disturbances also occur, the chance increases that the patient can not live independently anymore. He will get problems to find his way home, or to dress himself appropriately. Making his own meals may become dangerous. In this stage necessary care has to be provided by spouses, relatives, or neighbours. It is also possible that additional care such as meals-on-wheels, day-care facilities, and skilled nurses has to be organized. The length of time between living at home (or in a home for the aged) in these circumstances and admission to a Dutch Nursing Home is variable. It not only depends on patient characteristics such as behavioural disturbances, incontinence and wandering, the rapidity in which the symptoms occur, but also on the presence and the emotional and physical strength of the caregivers, their tolerance, the religious and moral duties the caregivers think they have to fulfil, and on the boundaries of professional home care, and the length of waiting lists.
When the dementia is more severe, the patient does not recognize his relatives anymore, he is unable to hold a reasonable conversation, and he becomes increasingly apathetic, or more agitated. Physical functioning is also impaired: he may become incontinent, and may loose his ability to walk. Increased efforts have to be made to guarantee adequate water- and food-intake. Many patients become bed-bound. The cause of death in these patients is mostly a pneumonia, dehydration, and cachexia [10].

Prevalence of dementia

Much research has been performed to the prevalence of dementia. Several reviews have summarized the available literature. With the help of a meta-analysis of European prevalence studies Hofman and colleagues found a prevalence rate of 2.7% for people between 65 and 75 years; this rate increased to almost 25% for people 85 years and above [11]. In almost all studies the prevalence increased with age [12]. Especially for mild dementia there is a great variety in prevalence rates [13]. This might be one of the reasons why Muskens found a much lower prevalence rate of 2% and 4% for people 65 years or higher [14]. There is a great variation in estimates of the number of patients with dementia in the Netherlands. According to the Alzheimer Stichting there are about 300 000 people suffering from dementia, including the beginning and very mildly demented stages. According to Bijl there are about 100.000 people with severe dementia [15], and about 20 000 of them reside in Dutch Nursing Homes which are especially designed for providing continuous care for those dementia patients who can not live at home anymore [16]. Furthermore about 5000 demented patients visit day care facilities [17].

A possible explanation for the great variation in the estimates of the number of dementia patients is that especially in the mild stages general practitioners are reluctant to label their patient as demented unless they are quite sure: a diagnosis of dementia can be very distressing for a mildly demented patient and his relatives; the prognosis of dementia is known as poor, and sooner or later an admission to a care facility is inevitable, because the dementia is almost always irreversible. This leads to the misunderstanding that nothing at all can be or even needs to be done anymore. Another reason for the reluctance to label a patient as demented is the difficulty in distinguishing between early dementia and depression [13]. Diagnosing dementia can also be very difficult in patients with a stroke which has caused impairment of neuropsychological functioning, and Parkinson's disease. Methodological issues can also cause differences in prevalence rates: dementia patients who do not visit the general practitioner can not be diagnosed as demented; in a study of O'Connor the general practitioner frequently did not correctly identify dementia [18]. On the other hand, general practitioners are in the best position to judge wether there is a functional decline in memory or cognitive functions [14].

Once a patient is admitted to a Dutch Nursing Home, the mean length of stay is about 3 years, but there is a great variation. Little is known about patient characteristics that explain this variability: not all patients are admitted at the same stage in the dementia process, the rapidity of progression of symptoms differs between patients, and other diseases may have a substantial influence on prognosis. The policy of a

Dutch Nursing Home regarding enteral feeding and other life-prolonging measures, hospital admissions, and the intensity with which life-threatening diseases are searched for and treated, will also influence prognosis. More insight in the natural course may lead to more insight in the dementia process, and to a more individualized prognosis. This information can be very helpful for patients and caregivers, for planning, and for decisions about diagnosis or therapy in which the life expectancy plays an important role. Nevertheless, until now this information is scarce.

Dutch Nursing Homes

Until now we have used the word "Dutch Nursing Home" to describe the facility in which the dementia patients reside. The Dutch word "verpleeghuis" is often translated in English as "nursing home". The medical care in Dutch Nursing Homes may better be compared with medical care in a "hospital geriatric service", a "rehabilitation ward" or a "long-stay ward" in the United Kingdom [19]. Also "nursing homes" in the United States are not quite the same as in the Netherlands [20]. In our country criteria for admission are much more explicit and a differentiation is made between indications for psychogeriatric reasons and for somatic reasons. Explicit attention to the combination of continual, (often) long-term, systematic, and multidisciplinary care is unknown in American nursing homes. Since 1989, physicians in the Netherlands have to follow a two-year educational program before they can be registered as "verpleeghuisarts" [21]. In this thesis the words "Dutch Nursing Home" and "Dutch Nursing Home physician" will be used. In the United States the nursing homes use external physicians, who give many of their consults by telephone [20]. Patients who have e.g. a pneumonia and get seriously ill, are usually admitted to a hospital [22]. In Dutch Nursing Homes they are usually treated within the facility. This thesis concerns the patients in whom there has been contact with the general practitioner, who has performed further action. The dementia is so severe that they are at least moderately demented according to the DSM-III-R criteria. This means that living independently is hazardous, and some degree of supervision is necessary [1]. Most of them are severely demented, and these patients have to be admitted to a Dutch Nursing Home. In 1983 there were 83 psychogeriatric Dutch Nursing Homes especially designed for patients with dementia. This number decreased to 67 in 1992, because more and more Dutch Nursing Homes are "combined", which means that they also admit people with somatic handicaps: the number of these combined homes increased from 96 in 1983 to 173 in 1992 [23]. The number of beds for patients with dementia increased from almost 20 000 in 1983 to almost 26 000 in 1992 [23].

Patients with dementia often reside in somatic Dutch Nursing Homes: Heeren found for instance that a large percentage of the patients above 85 years old were suffering from dementia [24].
Psychogeriatric Centre Stadzicht is a psychogeriatric Dutch Nursing Home just outside the centre of Rotterdam with a roman-catholic signature. It has a capacity of 261 beds and a day care facility. There is an observation ward, where every patient is residing during the first month after admission. After this period the patient is transferred to one of the eight nursing wards, which do not differ in patient population with regard to severity of dementia: the patient needs not to be transferred again when he becomes more demented. The population seems not to be different from other psychogeriatric Dutch Nursing Homes. For instance, the help - index at admission during the years 1984 to 1988 was about 6.8 (range 6.4 - 7.0), the same value as for patients admitted to psychogeriatric Dutch Nursing Homes in 1990 [25]. The flow rate ("doorstromingscoëfficient", the number of admissions and discharges divided by two times the number of beds) in 1989 and 1990 was 0.43 and 0.53; this was about the same as the mean flow rate of 0.47 in more than 40 other psychogeriatric Dutch Nursing Homes [25,26]. Stadzicht has admitted 140 patients to the hospital during the years 1985 - 1988: this implies about 135 hospital admissions per 1000 patients per year. This does not differ from hospital admission rates in other psychogeriatric Dutch Nursing Homes [27].

This study evaluates the prognosis of dementia patients after admission to a Dutch Nursing Home and tries to identify which characteristics known at admission have influence on prognosis. It contains two parts: survival (Chapter 1 - 5) and natural course (Chapter 6 - 7). Chapter 1 gives a review of the available literature on survival in patients with dementia. Chapter 2 describes the population under study and compares its mortality with the expected mortality according to Dutch vital statistics. In Chapter 3 is dealt with the predictive value of a Dutch behavioural rating scale. Chapter 4 evaluates the relationship between comorbidity, dementia and survival. Chapter 5 combines the information of Chapter 3 and 4, and describes a prognostic index which can be used for prediction of survival in individual patients. The second part of this thesis deals with two important aspects in the natural course of the dementia. Chapter 6 gives a description of the dependency over time, and in Chapter 7 it is investigated whether it is possible to identify fall-prone patients with some basic patient characteristics. Finally, Chapter 8 discusses the results and gives some reflections about the use of the results in the management of the demented patients.

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Chapter 1. Survival of patients with dementia: a review.

Dementia is a syndrome which is characterized by mental deterioration. During the last decades the interest in its clinical manifestations but also in its epidemiology has been growing. In early studies there was considerable heterogeneity in terminology. Uniformity increased with the introduction of criteria according to the NINCDS-ADRDA Work Group [1] and the DSM - III (- R) [2]. These criteria are presently generally used and comparisons between different types of dementia have become easier. Knowledge about the prognosis of demented patients is of considerable importance. On the individual level of patient-care one would like to be able to inform the patient and his family about the rate of progression of the dementia process, the symptoms which can be expected and the expected survival. This information can also be important in clinical decision making and for planning of institutional care. Studies on survival in dementia patients have led to more or less accepted conclusions such as:

- a higher survival rate for patients with SDAT (Senile Dementia Alzheimer's Type) than for patients with MID (Multi-infarct Dementia)
- a higher survival rate for women than for men
- a lower survival rate as compared to the general population (vital statistics)
- an increasing mortality with age
- a decreasing mortality over time, especially during the last decades.

The validity of these conclusions, which are uncertain due to differences in type of study population, diagnostic criteria and other factors, will be investigated by a systematic analysis of the literature on survival in dementia.

Material and methods

Material

In total, 90 papers in the field of medicine (e.g. psychiatry, neurology, geriatrics and internal medicine) and in the field of clinical psychology about prognosis and natural course in patients with dementia, are reviewed for information about survival. 41 Papers about 38 studies with quantitative and interpretable results were selected. In order to be included in this review, *criteria for diagnosis* should comprise at least retrograde amnesia and impaired cognition. As for *survival analysis methods*, only cohort based studies are selected that use either actuarial or product limit estimations of survival time T or report the proportion survivors, deceased, and lost to follow up after a certain time-period.

In general, the studies deal with one of the following *types of study-population*. Community based studies: in these studies, dementia patients in a well-described area should ideally have the same probability of being incorporated. The purpose of these studies is to give survival figures just after onset of dementia, or at first admission to the general practitioner. Outpatient clinic based studies: this type of study population includes attendants of dementia clinics, and psychiatry, neurology or internal medicine outpatient clinics. Nursing home based studies: in these studies, the patients reside in institutions designed for continuous care of people who are no longer capable of living at home. The hospital based studies comprise a mental or psychiatric hospital population. The study material comprises patients in whom (the evaluation of) the dementia itself was the main reason for admission, or patients known as suffering from dementia, in whom a somatic disease (comorbidity) was the direct cause of admission.

The first three types of study population reflect more or less the time course of the dementing process: people with dementia in a nursing home are on average more severely demented than patients with dementia living at home. Thus, one expects a survival decreasing from the first to the third category, although patients of the latter two categories may receive better care (prevention and recognition of poor nutritional state, early medical treatment of intercurrent illness). The papers are classified according to these four types of study population in Tables 1 - 4.

The *country* in which the study is conducted may reflect differences in basic survival rates of the general population, differences in availability of institutionalized care, patterns of referral, and differences in terminology.

The *year of study* is mentioned in order to investigate a possible increase in survival rates over the last decades. When this information is not available, we subtracted the maximum length of follow up from the *year of publication* in order to get a proxy for the year of study.

There always has been a great variability in terms for *diagnostic categories*, especially before 1980. In most studies the authors use other terms than SDAT and MID, such as senile psychosis, senile dementia, vascular dementia, atherosclerotic dementia and so on. To enhance interpretability these terms are replaced as carefully as possible by SDAT or MID. Thus, the criteria in the studies are not necessarily the same as used according to the NINCDS-ADRDA Work Group [1] or the DSM - III - R [2].

As life table mortality increases sharply with age and differs between males and females, examining the data stratified for *age* categories and *gender* is useful.

The severity of symptoms or degree of dementia is related to the progression of the dementia process and to prognosis. In the available literature subdivisions have been made into mild, moderate and severe or advanced dementia.

Methods

Two-year survival

Survival is reported in various ways, e.g. 50% survival time, 5-year survival, mean survival time. In order to make these results comparable, we computed the *two-year survival rate* for each study using an exponential approximation of the survivorship function [3]. The exponential survival function is described as $S_t = e^{-\lambda \cdot t}$, with a mean survival time $1/\lambda$.

The two-year survival rate S_2 can be computed with the estimate λ from the reported study into the equation $S_2 = e^{-2\lambda}$. λ can be computed by taking the inverse of the reported mean survival time or by $\lambda = -(\ln S_t)/t$. Two examples of computation of two-year survival rates from reported data are:

a) The study reports a five-year survival of 40%. This implies that $\lambda = (-\ln 0.4)/5 = 0.183$. The two-year survival will be $S_2 = e^{-2 \cdot 0.183} = e^{-0.366} = 0.69$.

b). The study reports a mean survival time of 5 years. This implies that $\lambda = 1/5 = 0.2$. The two-year survival will be $S_2 = e^{-2 \cdot 0.2} = e^{-0.4} = 0.67$.

If a paper reports survival rates for several follow up periods, but no two-year survival rates, the hazard rate and the estimated two-year survival rates are computed for each period, and the range of these rates is reported.

Results

The right-hand columns of Tables 1-4 give the estimated two-year survival rates for the studies according to type of study population. The other entries concern author's name, reference number, year of publication and/or year of study, country, category and study size. The category column is further subdivided into diagnostic categories or severity of symptoms.

Data stratified for age are hardly available and therefore lacking in the tables. Tables 3 and 4 give two-year survival rates for men and women separately. As these were sparse in community and outpatient based studies, no rates according to gender are given in Tables 1 and 2.

Type of study population

In general, survival depends on the reference population. See also Figure 1. There are large differences in results between the community based studies [4-14]: two-year survival rates range from 37% up to 86%. Unfortunately, only one study concerns a cohort of new cases in the community [11]. The other studies consist of a mixture of patients under different types of medical attention. Meaningful interpretation is hardly possible.

The two-year survival rate for patients visiting an outpatient clinic [15-21] is about 75% (range 65% to 95%). The favourable results of Heyman [16] may partly be explained by the relatively young patient group. Barclay [15] and Treves [22] also estimated the survival from onset of dementia, but they overestimate survival by not correcting for "survivors-only-bias" [23].

Nursing home patients seem to have a less favourable prognosis [24-31]. Generally they have a two-year survival rate after admission of about 50% (range 30% - 65%).

Several studies [32-35] are not considered because of an inadequate design for estimating valid survival rates. The results of Diesfeldt [32] are based on data from death logs from a 6 year period, and the estimations of Thompson [33] are based on data from death or discharge logs from a 10 year period. This introduces length-biased-sampling and thus gives an underestimate of survival. Diesfeldt [32] also estimated the survival from the time since onset of dementia, without correcting for "survivors-only-bias". Isaacs [34] gives survival rates for people who already were living in the nursing home up to several years. These will be biased towards lower survival rates when compared to rates after admission. The same bias is present in the study of Jacobs [35].

After admission to a mental or psychiatric hospital [36-50], patients have a two-year survival rate of about 40% (range 20 - 60%). The results of Go [42] have been adjusted to an age at admission of 65 years. The results of Duckworth [45] are based on a combination of mental, psychiatric and general hospital patients. Kaszniak [48] conducted his study in a general hospital.

Several studies are not considered. The survival rates of Kay [51] cannot be interpreted: they are not linked to a specified time period after admission. Goldfarb [52] only gives aggregated figures for survival after institutionalization for nursing homes, mental hospitals and homes for the aged, and no figures for hospitals and nursing homes separately. Seltzer [53] and Robinson [54] present agglomerate figures for inpatients and outpatients. The survival estimates of Christie [55] for the patients in the 1950's have the same bias as the study of Diesfeldt [32].

Survival in patients with SDAT versus MID - patients.

There are only small differences in survival between these two diagnostic categories. In general, earlier studies [37-39] show a somewhat more favourable prognosis for people with MID compared to people with SDAT, while many recent studies [5, 12, 15, 18, 43, 45, 50] have a slight opposite tendency. Differences in favour of SDAT vary between 5% and 15% in these recent studies.

Table 1. Estimated two-year survival rates for demented patients in community based studies

Author, reference	year of study / year of publication	country	category	number in sample	S_2
Rorsman [4,5]	47 / 85	NO	SDAT	35	0.74
			MID	41	0.65
			total	76	0.68
Rorsman [4,5]	57 / 85	NO	SDAT	45	0.88
		US	MID	53	0.77
			total	98	0.80
Schoenberg [6]	60 / 81	US	dementia	102	0.75-0.86
Schoenberg [7]	60 / 87	US	dementia	178	0.77
Nielsen [8]	61 / 77	SWE	severe	27	0.46
			mild	143	0.69
			total	170	0.65
Akesson [9]	64 / 69	SWE	severe	78	0.37-0.47
Jarvik [10]	67 / 80	US	dementia	31	0.69
Magnusson [11]	71 / 89	ICE	severe SDAT		0.82
			severe MID		0.87
			severe total		0.85
Molsa [12,13]	76 / 84	FIN	SDAT	218	0.59
			MID	115	0.49
			MIX	37	0.57
			total	370	0.56
Bergmann [14]	83 / 85	UK	dementia	100	0.68

Abbreviations: S_2 = two-year survival rate, FIN = Finland, ICE = Iceland, NO = Norway, SWE = Sweden, UK = United Kingdom, US = United States, MID = Multi Infarct Dementia, MIX = Mixture of MID and SDAT, (P)SDAT = (Pre) Senile Dementia of the Alzheimer's Type.

Table 2. Estimated two-year survival rates for demented patients in outpatient clinic based studies

Author, reference	year of study / year of publication	country	category	number in sample	S_2
Barclay [15]	79 / 85	US	SDAT	199	0.83
			MID	69	0.62
			MIX	43	0.61
			total	311	0.75
Heyman [16]	79 / 87	US	PSDAT	92	0.95
Walsh [17]	80 / 90	US	SDAT	126	0.87
Martin [18]	81 / 87	US	SDAT	134	0.85
			MID	41	0.80
			total	202	0.79
Hier [19]	81 / 89	US	SDAT	61	0.64
			MID	34	0.63
			total	95	0.64
Knopman [20]	82 / 88	US	mild SDAT	51	0.94
			severe SDAT	48	0.77
			total	99	0.85
Becker [21]	87 / 88	US	SDAT	86	0.85

Abbreviations: S_2 = two-year survival rate, US = United States, MID = Multi Infarct Dementia, MIX = Mixture of MID and SDAT, (P)SDAT = (Pre) Senile Dementia of the Alzheimer's Type

Survival according to age and gender.

Women have a better prognosis than men. In nursing homes [25,30,31], two-year survival rates for women are consistently higher than those for men (about 60% vs. 40%). In (mental) hospital based studies only more recent studies [39,42] give higher survival rates for women.

Only a few studies report age-specific survival rates. As can be expected, life expectancy decreases with increasing age. Zijlstra [30] for instance finds a two-year survival rate of 65% for people under 65 and 38% for people over 85. Nielsen [8] gives a mean survival time of 7.7 year for people between 65 and 70, and 3.8 year for people over 80. Roth [38] gives comparable figures.

Table 3. Estimated two-year survival rates for demented patients in nursing home based studies.

Author, reference	year of study / year of publication	country	category	number in sample	S_2 all	S_2 male	S_2 female
Peck [25]	63 / 78	US	dementia	203	0.66	0.53	0.70
Hazenberg [26]	66 / 79	NL	dementia	386	0.55		
Brody [27]	71 / 72	US	dementia	64	0.56		0.56
Vitaliano [29]	71 / 81	JAP	dementia	227	0.67	0.56	0.73
Zijlstra [30]	71 / 86	NL	dementia	582	0.53	0.37	0.62
Diesfeldt [31]	72 / 79	NL	dementia	266	0.31	0.22	0.35
				299	0.48	0.39	0.54
Van Dijk	82 / 92	NL	dementia	606	0.55	0.39	0.60

Abbreviations: S_2 = two-year survival rate, JAP = Japan, NL = Netherlands, US = United States.

Excess mortality

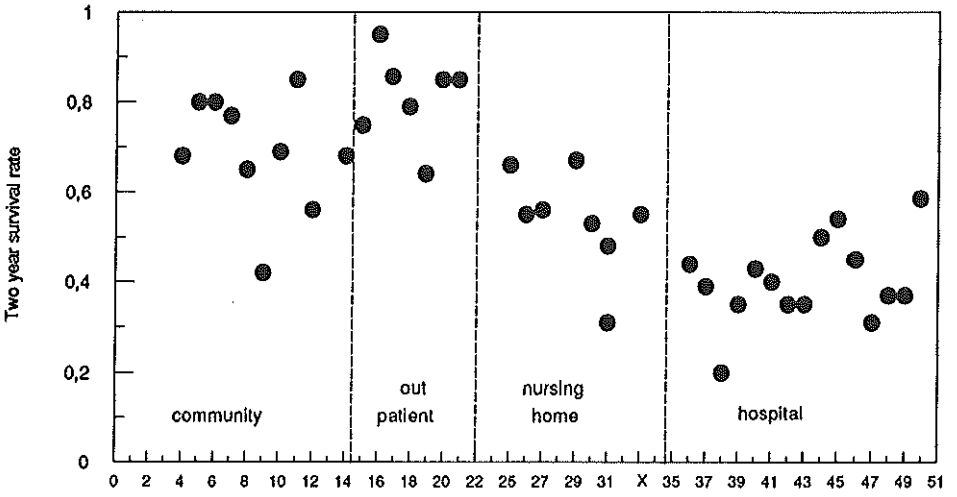
Several studies compare their survival rates with an (age-sex matched) standard population [4,6,9,11,15,16,26,36,37,43]. They all report a shorter survival for people with dementia. Other studies compare survival rates with control groups without dementia, evaluated at the same institution [18,24,36,40]. They all find lower rates for people with dementia. It seems that excess mortality increases with increasing duration of the dementia. Three studies [6,26,36] give an observed / expected ratio of survival 1 year after evaluation of 101% (community based), 79% (nursing home) and 56% (mental hospital). After 5 years, these figures are 77% , 49% and 27% respectively.

Year of study (time - trend)

In Figure 1, two-year survival rates are given for the different types of study population, and ranked according to year of study. The figure shows no clear improvement in survival rates over time, except maybe for the outpatient clinic population. However, all outpatient studies are conducted within a relatively short period (between 1979 and 1987). Gruenberg suggests a trend towards higher survival rates in

the Lundby Study [56], but these results are not statistically significant [4,5]. In hospital studies prognosis for SDAT may have become better over time, but no improvement in prognosis for MID can be found.

*Figure 1:Two-year survival rates for 38 follow up studies of demented patients. **



* Numbers on horizontal axis are reference numbers, ordered according to calendar time for each type of study population. Number 'X' represents the results of our own study.

Severity of symptoms

Several studies [8,11,18,20] give prognosis according to the severity of the dementia symptoms. As studies use different criteria for severity, it is not possible to compare results directly. Nevertheless, people with severe dementia have on average a worse prognosis than people with milder forms of dementia. This may cause the relatively low survival rate reported by Akesson [9], as he only considered severely demented people. It seems that factors concerning physical problems and dependency have some prognostic value [18,28,31]. Other (negative) prognostic factors include incontinence [28], EEG - disturbances [48] and lower results on tests or observation-scales [16,17,19,20,57]. Hardly anything is known about the influence of *comorbidity* on survival. Martin investigated the influence of comorbidity on survival in demented and non - demented people combined [18]. Unfortunately no results are given for dementia patients only. ECG - disturbances [30] and history of hypertension [19] are mentioned as negative prognostic factors in dementia.

The Rotterdam Nursing Home Dementia Study

Our own on-going follow up study in a nursing home for demented people shows a two-year survival rate of 0.55 after admission (see Table 3). The two-year product-limit survival rates are 0.60 for women (N=437) and 0.39 for men (N=169).

Table 4. Estimated two-year survival rates for demented patients in mental hospital based studies.

Author, reference	year of study / year of publication	country	category	number in sample	S_2 all	S_2 male	S_2 female
Kay [36]	31 / 62	SWE	dementia	82	0.44	0.46	0.42
Larsson [37]	35 / 63	SWE	SDAT	337	0.38	0.39	0.37
			MID	40	0.46	0.43	0.49
			total	377	0.39	0.39	0.38
Roth [38]	48 / 55	US	SDAT	76	0.18		
			MID	22	0.27		
			total	98	0.20		
Shah [39]	55 / 69	UK	SDAT	38	0.29	0.20	0.32
			MID	37	0.41	0.20	0.65
			total	75	0.35	0.20	0.44
Trier [40]	59 / 66	US	dementia	293	0.43		
Epstein [41]	59 / 71	US	dementia	139	0.40		
Go [42]	60 / 78	SWI	SDAT	216	0.40	0.20	0.47
			MID	132	0.27	0.18	0.32
			total	348	0.35	0.19	0.41
Varsamis [43]	64 / 72	CAN	SDAT	44	0.40		
			MID	16	0.23		
			total	60	0.35		
McDonald [44]	68 / 69	UK	dementia	57	0.50		0.50
Duckworth [45]	72 / 79	CAN US	SDAT	23	0.52		
			MID	5	0.40		
			total	35	0.54		
Christie [46]	74 / 82	UK	SDAT	100	0.50		
			MID	32	0.31		
			total	132	0.45		
Blessed [47]	76 / 82	UK	SDAT	97	0.31		
			MID	25	0.30		
			total	122	0.31		
Kaszniak [48]	77 / 78	US	dementia	47	0.37		
Naguib [49]	78 / 82	UK	dementia	40	0.37		
Christie [50]	84 / 90	UK	SDAT	193	0.65		
			MID	35	0.40		
			total	228	0.61		

Abbreviations: S_2 = two-year survival rate, CAN = Canada, SWE = Sweden, SWI = Switzerland, UK = United Kingdom, US = United States, MID = Multi Infarct Dementia, (P)SDAT = (Pre) Senile Dementia of the Alzheimer's Type

Discussion and conclusions

Discussion

In our view, survival in dementia can be viewed as the result of interaction of several factors:

a) mortality due to the risks of decreased cognition, memory and performance,

b) mortality due to the specific disease process (SDAT, MID) that interferes with brain function, and

c) mortality due to comorbidity (just as in every person, other diseases may be present).

Assessment of the validity of these assumptions requires separate survival estimations for *type of study population* and *severity of symptoms* (a), *diagnostic categories* (b), and existing *comorbidity* (c). In order to assess excess mortality, age- and sex-specific survival rates are necessary.

Unfortunately, not all of these factors are discussed in the majority of papers and most studies are not very careful in their operationalization of concepts. Many studies do not define the dementia syndrome itself, nor is it made explicit what is meant by severe as opposed to mild dementia, what differentiates SDAT from MID, etcetera. For example, not even the DSM - III - R criteria [2] describe how organic factors should be ruled out before the diagnosis of primary degenerative dementia has to be considered. There is still no agreement about criteria for clinical distinction between SDAT and MID. Some argue that "vascular dementia" is overdiagnosed [58], others that it is underdiagnosed [59]. Some studies use the Hachinski score [60] for discriminating between SDAT and MID. The cut-off point above which MID is considered as the most likely diagnosis varies from 4 to 7. On the one hand, this lack of operationalized criteria reflects lack of knowledge, but on the other hand knowledge can only grow when terminology is standardized.

Most studies only give the mean age at evaluation. This is too crude a summary in view of the steeply rising population mortality rates at older age. Furthermore, when the presence of an other disease is a reason for exclusion from the study [16,20,27] or when no statements are made about comorbidity, the influence of comorbidity on survival can not be analyzed.

But even studies that meet the demands for a quantitative interpretation are difficult to compare. Some studies have a short time of follow up or a small number of people under study. Furthermore different measures of survival are used. In order to compare these studies we used an exponential model of the survival function and computed the 2 year survival probability. The exponential distribution implies a constant

hazard rate λ. In many clinical studies the hazard rate is U - shaped and both extrapolating from 1 year survival to 2 year survival and interpolating from 5 year survival to 2 year survival may result in an underestimate. So, the results have to be interpreted with care.
Community based and hospital based studies are difficult to interpret. In community based studies it is very demanding and almost impossible to find a large enough and representative group of people with dementia of recent onset. Results are mostly based on institutionalized patients or people already under medical attention. In (mental) hospital based studies it is important to know the reason for admission: have patients been admitted for a clinical observation of their mental or psychiatric problems, or, in case of patients in whom the diagnosis of dementia already is obvious, because of somatic problems such as stroke or hip fracture? In the latter case one could expect a lower survival rate, corrected for the degree of dementia. In about 20% of the patients of Larsson [37], somatic disease was reported as a reason for admission. Shah [39] and Epstein [41] also signal this problem, but they give no figures.
Recent studies show a more favourable prognosis for SDAT as compared to MID. This is not surprising because important diseases such as stroke and peripheral vascular disorders are less often present in SDAT-patients. Sometimes these diseases are used as exclusion criteria for SDAT. Wolf-Klein suggested that Alzheimer patients are even healthier than other elderly patients [61], but the presented data do not give substantial evidence for this hypothesis, as the study suffers from selection bias [62,63].
However, before 1969 the general view was that patients with "atherosclerotic dementia" live longer than those with "senile dementia", see Shah [39]. An explanation for this change could be the following. MID-patients have always come under medical attention rather early in their specific dementing process: they have a sudden onset and a more fluctuating course, which is more alarming for the caregivers than the more gradually, incipient decrease in functions, found in SDAT - patients. But due to the general increase in attention to dementia, people with an incipient onset now come earlier under medical attention, and are therefore evaluated earlier in their disease process. This results in a longer survival after evaluation. This explanation is supported by a trend towards improving survival rates over time for SDAT in hospital studies and the absence of this improvement for MID.
Women have a better prognosis than men. This can partly be explained by the fact that also healthy women have a higher life-expectancy at any age. But women tend also to get earlier under medical attention: they usually are responsible for household-activities, which are more easily disturbed than when their husband becomes

demented. Moreover, they have a greater chance of being widowed and therefore of becoming dependent on other caregivers than their spouses. It might well be that prognosis for female patients and male patients is equal when severity of dementia , age and comorbidity are taken into account. We are currently testing this hypothesis. All studies in which mortality rates are compared with the standard population or other control groups find an excess mortality for people with dementia.
There is also an increase of mortality rates with age. Whether this not only reflects the age dependency of mortality rates in the general population, but also an increase in malignancy of the dementia itself, is not yet settled.
No increase in survival over the last decades could be found, although this has been suggested by several authors [15,47,50,56]. Probably the variability in criteria for dementia and its different categories over time, and in study population (gender, age, severity of dementia) is too large to find the expected improvement. An increase could have been expected for at least two reasons. First, life expectancy in the general population has been rising during the last fifty years. Second, there may be an improved survival for SDAT patients, who in general represent more than half of all dementia patients. As far as we know, there are no studies about the effect of specific medications such as oral physostigmine on survival. In these studies the outcome measures usually are scores on neuropsychological tests or behavioural rating scales [64,65].

Conclusions

Referring to the five statements in the introduction which reflect current opinion, we found evidence for the following three:

- Women seem to have a better survival than men, which is partly a result of a higher survival for women in general.
- There is a considerable excess mortality as compared to the general population.
- There is an increasing mortality with age.

The two other statements cannot be confirmed from this review:

- Differences in survival between patients with SDAT and patients with MID are small and not consistent.
- Evidence for a decreasing mortality over time could not be found.

Although we were able to investigate the validity of these statements, and give them a rough quantification, a more complete evaluation is only possible if future studies are better designed, and consider the factors influencing survival simultaneously.
We recommend that future survival studies should mention the type of the popula-

tion under study in detail. Results should be broken down according to age, sex and diagnostic category. Standard diagnostic classifications, like those from the NINCDS-ADRDA Work Group or the DSM - III - R should be operationalized and validated , and used as criteria of inclusion in a study. Prognostic factors such as comorbidity and severity of the dementia should be systematically recorded. Information about the rate of progression - measured with for instance the Blessed test [66] - which in itself already could be of considerable value in predicting further disease course, could also be evaluated on its value in predicting survival. The prognostic value of these factors should be expressed quantitatively, and if possible, in a multivariate way [18,19]. This will give us more insight in the interactions between factors which influence the disease course and survival. Furthermore it will enable us to give better-founded information to the patients and their relatives about the life expectancy with dementia.

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Chapter 2. The nature of excess mortality in nursing home patients with dementia.

Dementia affects as much as 5% of the population aged 65 or more in developed countries [1] and is one of the main causes for disability and institutionalization in the elderly [2]. An insight into its natural course and prognostic indicators may improve the management of dementia patients. Previous studies have indicated that dementia is associated with an increased mortality compared to vital statistics [3-7], and several personal and clinical characteristics, such as gender and age [8], type of dementia [9-13], severity of dementia as measured on several behaviour rating scales [10,14-18], or psychological tests [17,19-21] have been found to predict mortality. However, surprisingly few studies have reported stratified survival analyses for gender, age, type of dementia, or comorbidity. In a recent review of the subject we recommended that the prognostic value of variables should be expressed quantitatively, not only individually but also in combination with other variables [22]. The present report shows the results of an 8-year follow-up of patients with dementia in a nursing home and analyzes the nature of excess mortality because of dementia. An attempt is made to identify factors that have an effect on mortality in dementia patients.

Material and methods

Patients

The study population consists of 606 patients admitted between January 1, 1982 and December 31, 1988 to Stadzicht in Rotterdam, a nursing home facility specialized in the care of people with dementia. Follow-up data were collected until death or discharge, or until January 1, 1990. During the follow-up period 394 persons died and another 58 persons left the institution. On January 1, 1990, 154 persons were still living in the nursing home.

Admission to the nursing home may occur in several ways. A person with suspected dementia is referred by a general practitioner or a specialist to a regional institution for ambulatory psychiatric care. In cooperation with the nursing homes in Rotterdam, a multidisciplinary screening is carried out by a psychologist, a nursing home physician, and a social psychiatric nurse. Screening consists of a medical and a psychological examination and a clinical laboratory evaluation (blood evaluation and ECG). Information about social circumstances and problems with activities of daily life is gathered by the social psychiatric nurse. After evaluation the team

reaches one of the following conclusions:
a. The diagnosis of dementia is confirmed and the patient is placed on a waiting list. Admission will take place if and when appropriate care can no longer be provided outside of the institution.
b. The diagnosis of dementia is refuted and admission is denied.
c. The diagnosis of dementia is doubtful and the patient is referred for further evaluation either to a special observation department in the nursing home, or to a day care program, or to an internal medicine specialist, a neurologist, or a psychiatrist. Subsequently, a decision about diagnosis and admission is made.
In other cases, patients with established diagnoses of dementia are placed on the waiting list without screening. In still other cases the conditions at home necessitate an emergency admission without preliminary screening and confirmation of diagnosis. The admission is then used as a clinical observation.
After admission all patients first stay for about 6 weeks in the special observation department, where they are again evaluated medically and psychologically. Their functional and social capacities are assessed by means of a behavioural rating scale.

Methods

Criteria for dementia. Dementia was diagnosed according to criteria of the DSM - III - R [23]. Senile dementia of the Alzheimer's Type (SDAT) was diagnosed after exclusion of other causes of dementia and criteria are based on those for primary degenerative dementia in DSM - III - R. The diagnosis of multi-infarct dementia (MID) was based on the presence of a stepwise deterioration or a patchy loss of functioning, possibly variable throughout the day, or specific changes on a CT-scan (multiple infarcts) or EEG (focal or hemispheric lesions).
Behavioural Rating Scale. The BOP [= Beoordelingsschaal voor Oudere Patienten = Rating Scale for the Elderly [24]] is a behavioural rating scale derived from the Stockton Geriatric Rating Scale [25] and is widely used in the Netherlands. It consists of 35 measures of behavioural and cognitive impairment. Scores are derived on six subscales: Dependency, Social Disturbance, Physical Disability, Depression, Orientation and Communication, and Apathy. Examples of items are: "needs help with dressing", "does not understand other people", or "incontinent at night". Each item is scored on a 0 - 2 scale depending on the severity (no help, little help, much help) or frequency (never, sometimes, often) of the disability.

Comorbidity, secondary diagnoses. Heart failure, atrial fibrillation, hypertension, "chronic diseases" and "chronic impairment" , and "miscellaneous diseases and symptoms" (excluding previous hip operation) were diagnosed by the nursing home physician during the 6-week observation period, or mentioned in a letter from a specialist or a geriatric physician and confirmed by the nursing home physician. The diagnoses myocardial infarction, stroke and TIA (transient ischaemic attack) were made by a specialist prior to admission or occurred during the observation period. Incontinence was considered as present if defined by the nursing staff as a persistent problem. "Sporadic diagnoses" include diseases and symptoms with a prevalence of less than 5%.

Survival analyses. Survival was calculated from time of admission and estimated by the product-limit method [26]. This method enables us to use the data of patients with incomplete survival data because of loss to follow-up (discharge) or no death before the end of study (January 1, 1990). Differences in survival between subgroups were tested by the log-rank test ($p < .05$). The proportional hazards regression model was used for analysis of prognostic factors [27]. This model is based on the hazard $\lambda(t)$, which is the instantaneous risk of dying in a short interval after time t for a person alive at time t after admission. It assumes that the hazard for a certain value of a prognostic factor is a constant coefficient times the hazard for an other value of the same prognostic factor. The model has the form

$\lambda_i(t) = \lambda_0(t)\exp(\beta_1 \cdot z_{1_i} + \beta_2 \cdot z_{2_i} + \ldots + \beta_n \cdot z_{n_i})$, in which $\lambda_0(t)$ is the baseline hazard and $\lambda_i(t)$ is the hazard for an individual i, $\beta_1 \ldots \beta_n$ are the regression coefficients for the prognostic factors 1 ... n in the model and $z_{1_i} \ldots z_{n_i}$ are the values of an individual i for these variates. The survival function for an individual may be expressed as

$$S_i(t) = S_0(t)^{\exp\left(\beta_1 \cdot z_{1_i} + \beta_2 \cdot z_{2_i} + \ldots + \beta_n \cdot z_{n_i}\right)}$$

Excess mortality. The relative mortality (RM) is defined as the ratio between the observed number of deaths in the study population (OBS), and the expected number of deaths derived from vital statistics (EXP) [28]. The average attributive mortality per person (AM / N) is defined as (OBS - EXP) / N, where N = the number of patients. To assess the excess mortality at different periods after admission, the AM is divided by the number of person-years of follow-up at these time periods.

The expected number of deaths (EXP) represents the mortality in the general population. Demented patients will have an increased hazard of dying. Two models can be of help in studying the nature of their excess mortality [29]. An additive model assumes that the effect of dementia on mortality is independent from other causes of

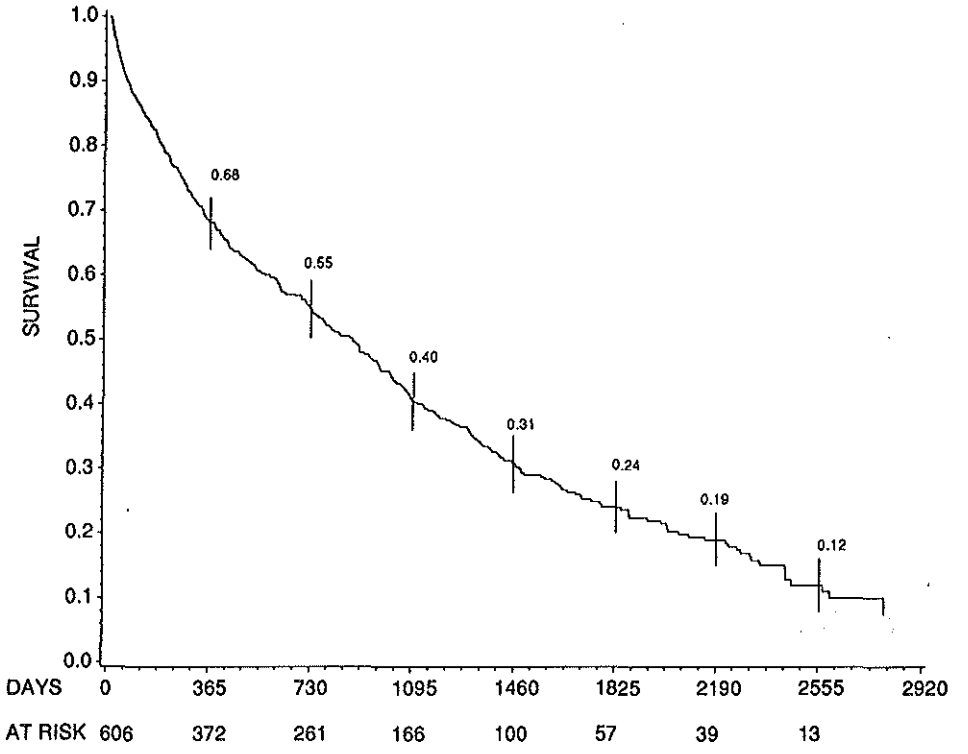
death. Mathematically, the mortality increases with a certain amount A because of the dementia: OBS = EXP + A. Because EXP clearly increases with age, stratified analyses are needed. If A is the same for all age groups, then we conclude that dementia has a simple additive effect on mortality: the attributive mortality per person will be constant over age, and the relative mortality, which equals 1 + (A / EXP), will decrease with age.
A multiplicative model assumes that the dementia increases the mortality of other causes. Mathematically, the expected mortality is multiplied with a certain factor F: OBS = EXP * F. If F does not change with age, we conclude that dementia has a simple multiplicative effect on mortality: the relative mortality will be constant over age, and the attributive mortality per person (AM / N), which equals EXP * (F - 1) / N, will increase with age.

Results

General characteristics
Of the 606 patients admitted, 437 were women. Mean age at admission was 80.8 years (± 6.8 year) for all patients, 79.6 for men (SD 7.3) and 81.3 for women (SD 6.6). The mean duration of dementia before admission in 556 patients was 5 years (SD 3.2 year) and did not differ between men and women. When compared to men, women were more often widowed and more often referred from homes for the aged. The proportion of MID among men was higher than that among women (32% vs. 9%). In 12 patients (6 men and 6 women) the type of dementia was not established within the observation period (Table 1).

Survival
Gender and age. The product-limit survival curve for the entire study population indicated a 55% and 24% survival at 2 and 5 years after admission, respectively (Figure 1). At every age women had higher survival rates than men (Table 1). In the proportional hazards regression model, age and gender were both related to survival: the hazard can be expressed as $\lambda_i(t) = \lambda_0(t)\exp(0.66*gender + 0.046*age)$
where gender = 1 for men and gender = 0 for women and age is in years. These results imply that at every time interval after admission the risk of dying is nearly twice as high for men than for women of the same age and that the risk of dying increases by nearly 5% per year of age.

Figure 1: Product-limit survival - curve for the nursing home population. The 1-year, 2-year etc. survival rates with their 95% confidence intervals are indicated in the figure.



Diagnostic category. SDAT patients (N=503) had a 16% higher two-year survival rate than MID patients (N= 91). This difference, which is statistically significant, is partly explained by the preponderance of MID among males. The differences were 7% for men and 13% for women. In the proportional hazards regression model with age and gender, the hazard of dying for MID was 1.5 times the hazard for SDAT (95% confidence interval 1.1 - 2.0).

Table 1. Two-year survival rates, by age, type of dementia and duration.

	All		Men		Women	
	relative frequency (%)	two-year survival rate (%)	relative frequency (%)	two-year survival rate (%)	relative frequency (%)	two-year survival rate (%)
Total (N=606)	100	55	28	39	72	60
Age		[a]				[a]
- 69	6	73	9	64	5	79
70 - 74	11	64	14	41	10	72
75 - 79	26	56	28	32	25	67
80 - 84	30	61	24	41	32	66
85 - 89	19	41	18	33	19	43
90 -	8	32	7	23	8	34
Type of dementia		[a]				
SDAT	84	57	65	41	90	62
MID	14	41	31	34	9	49
unknown	2	38	4	56	1	31
Duration		[b]				
≤ 3 year	35	47	37	29	34	52
3 - 6 year	36	61	33	48	37	65
≥ 6 year	29	61	30	41	28	68

a $p < .05$, log-rank test
b $.05 < p < .10$, log-rank test
(footnotes relate to survival rates just below)

Marital status and place of residence. After stratification for gender, there were no significant differences in survival for marital status. Married (N=110, 65%) and widowed (N=47, 28%) men had two-year survival rates of 39% and 40% respectively. For married (N=91, 21%) and widowed (N=293, 67%) women these rates were 61% and 58%.

People coming from the homes for the aged (N=110, 18%), or hospitals (N=118, 20%) had somewhat lower two-year survival rates (46% and 49%) than those coming from other nursing homes (N=102, 17%) or from their own house (N=258, 43%). They had two-year survival rates of 59% and 60%, respectively. Eighteen patients came from other places and their two-year survival rate was 56%.

Table 2. Two-year survival rates, by severity of dementia and comorbidity.

	relative frequency (%)	two-year survival rate (%)		relative frequency (%)	two-year survival rate (%)
BOP (N = 570) *	100	56	*Comorbidity (N=606)*		
Dependency [a]			*Cardiovascular diseases*		
0 - 16	40	74	myocardial infarction [a]	6	29
17 - 28	40	47	heart failure [a]	8	32
29 - 46	20	43	atrial fibrillation [a]	9	30
			hypertension	10	54
Social Disturbance			stroke	14	50
0 - 2	51	57	transient ischaemic attack [a]	8	38
3 - 10	49	55			
Physical Disability [a]			*Chronic major diseases*		
0 - 2	63	67	M. Parkinson [a]	14	33
3 - 6	37	39	chronic lung disease	9	44
			diabetes mellitus	10	40
Depression [a]					
0 - 2	59	62	*Acute illness*		
3 - 6	41	48	hip fracture	7	46
			pulmonary infection [a]	10	28
Orientation [a]			urinary tract infection	16	51
0 - 4	54	61			
5 - 8	46	51			
			Miscellaneous diseases and symptoms		
Apathy [a]					
0 - 7	49	70	anaemia [a]	5	25
8 - 14	51	43	pressure sores [a]	7	31
			malignancies [a]	5	30
			dizziness	8	49
			edema	26	57
			dyspnoea [a]	13	44
Chronic impairment			previous hip operation	13	45
(N=606)	16	41			
hearing impairment [a]	25	43	sporadic diagnoses [a]	34	45
visual impairment [a]	25	52			
fecal incontinence	46	47	no diagnosis [a] **	14	68
urinary incontinence [a]			≥ 1 diagnosis	86	52

* BOP missing (N = 36): two-year survival rate = 25 %
** no cardiovascular diseases, chronic major diseases, acute illness or miscellaneous diseases and symptoms
a $p < .05$, log-rank test

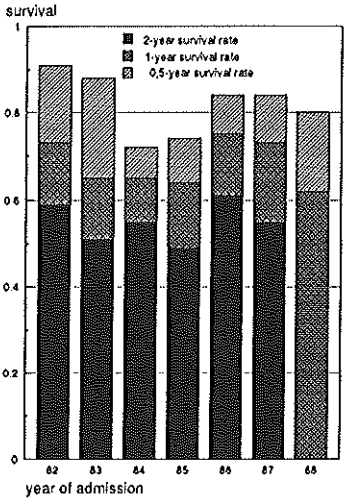
BOP. For the 6 subscales, patients were categorized in 2 or 3 subgroups according to their scores (see Table 2). With the exception of Social Disturbance, all subscales showed statistically significant higher survival rates for patients with lower degrees of impairment. The subscales Dependency, Physical Disability, and Inactivity had the highest predictive value. The pattern remained unchanged after stratification for

gender, and for each category survival was higher for women. The BOP was missing in 36 patients: for 13 patients the first BOP was only completed after the observation period. Fifteen patients died and 3 patients left within 6 weeks. For the other 5 patients the reason is unknown.

Comorbidity. Comorbidity was associated with reduced survival. The most striking differences were found for myocardial infarction, heart failure, atrial fibrillation, Parkinson's disease, respiratory tract infection, anemia, pressure sores, and malignancies. Patients with any of these diseases had a two-year survival rate of 29 - 38%. Surprisingly, hypertension or stroke were not associated with increased mortality rates. Patients with one or more of the diagnoses listed in Table 2 had a 16% higher two-year mortality than those without either of these diagnoses.

Secular trend. The half-, one- and two-year survival rates for each year of admission did not show any improvement over time (Figure 2). In terms of severity of dementia measured with the BOP, there was no trend toward a more impaired population at admission. An absence of improved survival can therefore not be explained by an increase in severity at admission.

Figure 2: Survival rates by year of admission in the nursing home.



Excess mortality

When compared to the general population, the relative mortality of patients with dementia during the first two years after admission was 3.0 for men and 2.4 for women (Table 3). For both sexes the RM decreased with age. For instance, the RM for women under 70 was 8.4, and for women over 90 the RM was only 1.7. The average attributive mortality was 0.35 per man and 0.22 per woman, which means that during the surveyed two-year period, dementia was associated with the death of 60 male patients in a population of 169 and 94 female patients in a population of 437. For both sexes the AM per person did not change with age. For instance, the 2-year mortality increased with (5 - 0.8)/16 = 0.26 per person for men under 70, and increased with (7- 3.8)/11 = 0.29 per person for men over 90. The decreasing RM over age, and the constant AM per person over age, suggest that the excess mortality from dementia may be described by one additive factor (see Methods).

Table 3. Observed and expected number of deaths after 2 years of follow-up, and the relative mortality, and the average attributive mortality per person due to dementia.

Gender Age	N	number of deaths observed	expected	relative mortality	attributive mortality per person
Men					
-69	16	5	0.8	6.1	0.26
70-74	24	10	1.9	5.3	0.34
75-79	47	30	7.2	4.2	0.49
80-84	41	20	8.1	2.5	0.29
85-89	30	18	8.5	2.1	0.32
90-	11	7	3.8	1.8	0.29
total	169	90	30.4	[a] 3.0	[b] 0.35
Women					
-69	21	4	0.5	8.4	0.17
70-74	45	12	2.2	5.4	0.22
75-79	110	32	9.4	3.4	0.21
80-84	139	44	20.5	2.1	0.17
85-89	85	45	20.2	2.2	0.29
90-	37	23	13.3	1.7	0.26
total	437	160	66.0	[c] 2.4	[d] 0.22

χ^2 - test for homogeneity of relative resp. attributive mortality (5 df):
a $\chi^2 = 14.05$, $p < .025$
b $\chi^2 = 2.40$, $p > .25$
c $\chi^2 = 22.52$, $p < .025$
d $\chi^2 = 2.32$, $p > .25$

An analysis of the excess mortality at different periods after admission revealed that the AM per person year of follow-up was high during the first months after admission and declined thereafter (Table 4).

Table 4. The attributive mortality (AM) per person-year (PY) at risk at different periods after admission.

	Men		Women	
period after admission	attributive mortality	attributive mortality per personyear	attributive mortality	attributive mortality per personyear
0-1 month	12.5	0.92 (0.45-1.63) *	19.0	0.54 (0.31-0.86) *
1-2 months	10.8	0.97 (0.44-1.77)	7.2	0.22 (0.06-0.50)
2-6 months	7.6	0.20 (0.05-0.42)	32.3	0.27 (0.17-0.39)
0.5-1 year	23.1	0.51 (0.30-0.79)	24.1	0.15 (0.08-0.24)
1-2 years	14.6	0.23 (0.10-0.40)	23.1	0.09 (0.04-0.16)
2-4 years	15.2	0.25 (0.10-0.44)	41.4	0.15 (0.09-0.21)
0-4 years	60.6	0.26 (0.18-0.36)	113.6	0.13 (0.10-0.17)

* 95% confidence interval

Discussion

As in previous reports [22], patients with dementia were found to have a worse survival than the general population. After admission to a nursing home the two-year survival rates of women and men with dementia were 60% and 40% versus 85% and 80% in an age-matched sample of the general population.

Excess mortality. The most interesting finding was that dementia seemed to have a predominantly additive, and not a multiplicative effect on mortality in nursing home patients. This suggests that dementia must be primarily regarded as an independent competing mortality risk, and an increased risk of dying in case of a pneumonia would be the same for patients with and without dementia. If the effect had been multiplicative, dementia could be regarded as a factor which primarily increases the risks of other causes of death (for instance, an increased risk of dying in case of a pneumonia is higher for patients with than for patients without dementia). One

might have expected a partially multiplicative effect, because people with dementia may have a greater chance of dying as a result of malnutrition and diseases such as pulmonary infections, urinary tract infections and pressure sores, and malnutrition. On the other hand, Dutch nursing homes guarantee an adequate food-intake and a rapid and adequate recognition and treatment of illnesses.

The reference population is the general population, and thus includes patients with dementia. This means that in the expected number of deaths a proportion of deaths from patients with dementia is included. Thus if the reference population consisted of nondemented patients only, the excess mortality would be larger. As the prevalence of dementia steeply increases with age [7,30], this is especially the case for the oldest age-groups. As a consequence, the differences in relative mortality between age-groups become smaller than those shown in Table 3, and there may be a trend toward higher attributive mortality with age. However, exploratory calculations suggest that these changes are small, and they do not invalidate our conclusion that the effect of dementia is predominantly additive. For example, a prevalence of dementia in women below 70 years of about 1% [30] will result in a relative mortality of 8.7 (was 8.4), and an attributive mortality of 0.17 (was 0.17). For women between 80 and 85 years the prevalence of dementia in women may be about 10% [3,30]. The relative mortality then will be 2.5 (was 2.1) and the attributive mortality 0.19 (was 0.17).

The relationship between dementia and excess mortality might partly result from a difference in the prevalence of other diseases between patients with and without dementia. This applies in particular to the first period of follow-up, because admission to a nursing home (or hospital) is often triggered by acute conditions with high short-term mortality such as cerebrovascular accidents and hip fractures. In 1963, Larsson and colleagues described this experience in relation to excess mortality [31]. Therefore, the relatively high prevalence of comorbidity just after admission will give an overestimation of the mortality that can be attributed to the dementia itself (see Table 4). Later on, with the available continuous care and after successful treatment of acute diseases, the prevalence of comorbidity and the mortality decline to levels more close to those in the general population. It seems that this decreased hazard affected the size, but not the nature of the excess mortality: calculations similar to those of Table 3, but based on mortality in the period between 2 and 4 years after admission, when the attributive mortality was lower (see Table 4), also suggested a constant additive effect. In summary, it seems that dementia has an

additive effect on mortality in a nursing home. A multiplicative effect, if present, is of minor importance, and would require a very large study for a reliable identification.

Prognostic factors. Gender, age, and severity of dementia according to a behaviour rating scale were prognostic indicators for survival, thereby confirming earlier studies. Comorbidity also had predictive value. Patients with SDAT had a somewhat better prognosis than those with MID. Quantitative conclusions about a better survival for SDAT patients without stratification for gender should be viewed with skepticism in view of the higher proportion of men among MID patients than among SDAT patients [9-13]. Furthermore, as in other studies, it was sometimes difficult to differentiate between SDAT and MID. A CT - scan was only made in a small number of cases. Postmortem evaluation of the diagnosis by autopsy is uncommon in Dutch psychogeriatric nursing homes. Strokes and TIA's were more prevalent in MID patients (35% and 13% respectively), but also occurred in 11% and 7% of the Alzheimer patients. Hypertension had a prevalence of 10% in both groups.

There was no trend toward improved survival over time. Studies conducted since 1966 in other nursing homes in the Netherlands showed about the same survival rates as our study [22]. The severity of dementia as measured with the BOP was also about the same. This suggests that no observable changes in survival have occurred over a 20-year period in Dutch nursing homes.

It should be noted that our patients represent dementia patients admitted to a Dutch nursing home facility. At admission, most patients were in stage 6 (severe cognitive decline) of the Global Deterioration Scale of Reisberg et al. [32]: 70% of the patients did not know in which institution they were, about 50% were incontinent, and 80% needed help when dressing. With respect to the (lack of) generalizability of our results, it would be interesting to investigate whether the relation between dementia and excess mortality is the same in nursing homes in other countries, and in patients who live in the community (often with a less severe dementia). A careful description of the population under study can be of help in comparing results, and in explaining possible differences in outcome.

Figure 1 shows that after the first year about 3 out of 4 patients will survive each subsequent year. The most important implication of this is that nursing homes should not be viewed as a place where people are waiting for their death, but as a living arrangement where they have a right to appropriate care. Consequently, just as in other patients, it can be important to individualize treatment-choices for intercurrent diseases in demented patients according to their chances, value judgment and prospects for improvement of well-being. This will, admittedly, not be easy. As

a first step, we will investigate methods for estimating the prognosis for individual patients by the joint evaluation of relevant prognostic factors. Such prognosis could be used for cautiously informing the patients' relatives and possibly also for individualized decision-making in dementia patients.

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Chapter 3. A behavioural rating scale as a predictor for survival of demented nursing home patients.

About 20000 (1.5%) Dutch inhabitants over 65 years of age reside in nursing homes because of dementia [1]. Their survival after admission ranges between a few days and more than 10 years, with a mean of about 2.5 years. This wide range provides only little information to the interested parties. Close relatives of the demented patient are often very interested in his prognosis. A nursing home physician needs prognostic information, for example, when he is considering offering his patient an operation because of a senile cataract. And health planners combine epidemiological and prognostic information when addressing questions of demand and turnover in nursing homes, and how these depend on admission criteria. Age and gender provide some prognostic differentiation [2,3], but more knowledge is needed.
The prognostic value of behavioural rating scales for assessing severity of dementia has been studied before. Measures of dependency in activities of daily life, physical impairment, and inactive behaviour appeared to be associated with survival [4-7]. Most studies however were carried out in a univariate or qualitative way. No attempt was made to study the joint effect of prognostic factors on survival.
In the present study of survival in dementia patients we use multivariate, quantitative methods in order to assess the information provided by a behavioural rating scale and to identify the subscales and items which particularly have prognostic value. The resulting model can be regarded as a step towards a more individual prognostic evaluation of dementia patients who are admitted to a nursing home.

Methods

Patients

The Psychogeriatric Centre Stadzicht in Rotterdam, The Netherlands, is a nursing home which serves about 260 patients, who are suffering from dementia of various etiologies. All 606 patients, 437 women and 169 men, admitted between January 1st, 1982 and December 31, 1988 were included in this study, and followed until death or discharge, or until January 1st, 1990. The mean age at admission was 80.8 year for the whole cohort, 81.3 years (SD 6.6) for women and 79.6 years (SD 7.3) for men. Dementia was diagnosed according to criteria of the DSM - III - R [8]. The mean duration of the dementia before admission was 5.1 years (SD 3.2). One third of the patients was married at admission, and 56% widowed. The place of living before

admission was their own house in 42%, a home for the aged in 18%, another nursing home in 17%, and a hospital or other institutions in 23% of the patients. A more detailed description of the study population is presented elsewhere [3].

Methods

BOP. The BOP (Beoordelingsschaal voor Oudere Patiënten), which is translated as Rating Scale for Elderly Patients, is used in many nursing homes in the Netherlands [9]. The BOP contains 35 items about behavioural and cognitive impairment. Nurses who take care of the patient score each item on a 0 - 2 scale with higher scores indicating more severe or more frequent disability. The item scores are used to calculate sumscores on six subscales: Dependency, Aggressiveness, Physical Disability, Depression, Orientation & Communication, and Apathy. In this study, the 35 BOP items, the 6 subscales, and the patients' age and gender are the possibly predictive variables. In the analysis, we used the BOP-scores measured for the 569 persons (410 women and 159 men) who had a completed assessment at the end of the observation period, about 1 month after admission. The BOP was not completed in the remaining 37 patients (6%), because of early death (17) or other reasons (20).

Like the rating scale of the CAPE (the Clifton Assessment Procedures for the Elderly [10], the BOP is derived from the Stockton Geriatric Rating Scale [11]. These three scales have 14 items in common. This enabled us to assess the prognostic value of that part of the CAPE - rating scale that overlaps with the BOP. Sumscores could be calculated on the Apathy and the Communication Failure subscales of the CAPE.

Survival is estimated by the product-limit method. Statistically significant differences in survival between subgroups are identified by the log-rank test ($p < .05$) [12]. Multivariate analysis of prognostic variables is carried out using proportional hazards regression models [13]. The log-likelihood is used as a goodness-of-fit statistic: the less negative its value, the more closely the model fits the observed data.

When using a proportional hazards model, for each patient the *hazard* of dying at time t is estimated by the equation

$$\Lambda_i(t) = \Lambda_{mean}(t) * \exp(\beta_1 \cdot z_{1_i} + \beta_2 \cdot z_{2_i} + \ldots + \beta_n \cdot z_{n_i} - \beta_{mean}) \quad (1)$$

For each patient the *survival* chance is estimated according to the equation

$$S_i(t) = S_{mean}(t)^{\exp\left(\beta_1 \cdot z_{1_i} + \beta_2 \cdot z_{2_i} + \ldots + \beta_n \cdot z_{n_i} - \beta_{mean}\right)} \quad (2),$$

where $\Lambda_i(t)$ is the hazard of dying for an individual i at time t, $\Lambda_{mean}(t)$ is the hazard of dying for someone with a mean score on all selected variables, $S_i(t)$ is the chance of survival for an individual i at time t, $S_{mean}(t)$ is the chance of survival at time t for someone with a mean score on all selected variables, $\beta_1 \cdot z_{1_i} + \beta_2 \cdot z_{2_i} + \ldots + \beta_n \cdot z_{n_i}$ is the sumscore for an individual i with

scores z_1 .. z_n on the variables $\beta_1..\beta_n$, where $\beta_1..\beta_n$ are the natural logarithms of the rate ratios shown in Table 3, and β_{mean} is the sumscore for someone with a mean score on all selected variables.

Two regression models are developed. Model 1 uses the BOP-items to predict survival, and Model 2 the BOP-subscales. Because we want to investigate the additional value of the BOP - variables above that of gender and age, the latter ones are forced into the two models before the forward selection of the BOP - variables starts. The reference model is based on age and gender only. The items and scales are entered or removed in a stepwise forward selection mode on the basis of tail probabilities ($p < .10$ and $p > .15$ respectively) from a likelihood ratio test statistic: a variable is only selected into the model if it gives enough additional prognostic information above that provided by the variables already in the model.

Model 1 was evaluated in detail. In order to avoid overoptimism, a split-half approach was used. The entire cohort was randomly divided into 2 equally sized subgroups. The stepwise forward selection was performed on the patients of one subgroup (the training sample), and the resulting model was used for estimating survival chances for the patients in the other subgroup (the validation sample). This process was repeated in such a way that every subgroup (and thus every patient) acted as a validation sample once. The patients were ordered according to their predicted survival chances into 4 groups with a "favourable", a "moderate", a "poor" and a "very poor" prognosis. The predicted survival chances in these 4 groups were compared with the observed survival rates in order to assess the reliability of the model predictions.

Results

Subscales

The subscales Physical Disability, Orientation & Communication and Apathy have one, four and five items in common with the subscale Dependency. It is therefore not surprising that they are highly correlated with that subscale (Pearson's r~0.7). The correlation between Apathy and Physical Disability is 0.6. The correlations between the remaining subscales are weaker and vary between 0 and 0.4. Men score on average somewhat higher on the subscales Dependency, Apathy and Aggressiveness than women (t-test, $p < .05$), see Table 1.

Survival

The two-year survival rate for the entire cohort (569 patients) is 56%. Except for Aggressiveness, scores on the subscales are significantly related with survival (log rank, $p < 0.05$), see Table 1. For all subscale scores, survival rates for women are significantly higher than for men.

Table 1. Scores on the behavioural rating (BOP) subscales and two-year survival rates in 159 male and 410 female institutionalized patients with dementia.

	Men (N = 159)			Women (N = 410)		
subscale	mean	two-year survival rate (relative frequency)		mean	two-year survival rate (relative frequency)	
All patients		40% (100%)			62% (100%)	
Dependency	21.3			19.3		
0 - 16		63% (30%)	*		76% (43%)	*
17 - 28		34% (45%)			52% (38%)	
29 - 46		27% (25%)			51% (19%)	
Aggressiveness	3.9			2.9		
0 - 2		39% (40%)			62% (55%)	
3 - 10		40% (60%)			63% (45%)	
Physical Disability	2.2			2.3		
0 - 2		48% (67%)	*		75% (61%)	*
3 - 6		25% (33%)			43% (39%)	
Depression	2.2			2.4		
0 - 2		48% (63%)	*		68% (58%)	*
3 - 6		27% (37%)			55% (42%)	
Orientation & Communication	4.3			4.3		
0 - 4		43% (52%)			67% (55%)	*
5 - 8		37% (48%)			57% (45%)	
Apathy	8.0			7.2		
0 - 7		58% (40%)	*		73% (52%)	*
8 - 14		27% (60%)			50% (48%)	

* log-rank test: $p < .05$

Individual items of the Physical Disability, the Apathy and the Dependency subscale are of considerably prognostic value (Table 2). Several clearly behaviourally anchored items, such as "needs help when eating", "needs help when walking", "needs help when dressing", "incontinent at night" and "incontinent during the day" show large differences in two-year survival rates between patients with a score of 0 (no help needed, no impairment) and patients with a score of 2 (much help needed, severe impairment). For instance, the patients who need no help when walking have a two-year survival rate of 73%, whereas patients who need much help when walking have a two-year survival rate of 36%. The items of the Aggressiveness scale have hardly prognostic value. The items "responds to his name" (OC4) and "privileges to leave the ward" (A7) have practically empty categories. Inference regarding these items is therefore limited; they are excluded from further analyses.

Table 2. Two-year survival rates for scores on the 35 items of the behavioural rating (BOP) scale. Relative frequencies are given in brackets. Items with statistically significant differences in survival rates are indicated.

	item	description of item	two-year survival rate (relative frequency)		
			score 0	score 1	score 2
		Dependency (D)			
**	D1	needs help when eating	66% (39%)	55% (42%)	39% (19%)
**	D2	incontinent during the day	67% (52%)	49% (16%)	43% (32%)
**	D3	does not make himself understood	64% (47%)	48% (39%)	56% (14%)
**	D4	unable to find his way around the ward	56% (8%)	69% (20%)	53% (72%)
	D5	urinates and defecates at the wrong place	57% (71%)	55% (12%)	53% (17%)
	D6	unwilling to do things asked of him	59% (41%)	55% (54%)	49% (5%)
	D7	engages in useless repetitive activity	56% (48%)	67% (13%)	53% (39%)
	D8	makes repetitive vocal sounds	61% (60%)	50% (17%)	49% (23%)
**	D9	drowsy during day-time	68% (52%)	50% (28%)	37% (20%)
**	D10	incontinent at night	68% (51%)	51% (10%)	44% (39%)
**	D11	needs protection from falling out of bed	63% (68%)	45% (3%)	42% (29%)
*	D12	objectionable during the night	60% (76%)	47% (14%)	44% (10%)
*	D13	restless at night	59% (78%)	50% (14%)	38% (8%)
		Aggressiveness (Ag)			
	Ag1	threatens verbally to harm others	57% (65%)	60% (19%)	50% (16%)
	Ag2	accuses others of harming him	55% (49%)	55% (21%)	60% (30%)
*	Ag3	hits and kicks other patients	57% (76%)	57% (15%)	46% (9%)
	Ag4	objectionable during the day	56% (53%)	59% (22%)	54% (25%)
*	Ag5	angry easily	58% (41%)	60% (32%)	49% (27%)

Table 2 (continued)

	item	description of item	two-year survival rate (relative frequency) score 0	score 1	score 2
		Physical Disability (PD)			
**	PD1	needs protection from falling out of chair	61% (86%)	21% (5%)	34% (9%)
**	PD2	needs help when walking	73% (46%)	48% (28%)	36% (26%)
**	PD3 #	needs help when dressing	71% (21%)	63% (36%)	44% (43%)
		Depression (De)			
*	De1	sad	62% (23%)	59% (37%)	51% (40%)
**	De2	utters physical complaints	63% (43%)	58% (22%)	47% (35%)
*	De3	weeps easily	59% (81%)	54% (10%)	40% (9%)
		Orientation & Communication (OC)			
	OC1 #	knows in which institution he is	68% (7%)	58% (23%)	55% (70%)
	OC2 #	knows any of personnel by name	78% (3%)	53% (4%)	56% (93%)
*	OC3 #	understands others	62% (44%)	53% (50%)	45% (6%)
	OC4 #	responds to his name	57% (87%)	44% (12%)	88% (1%)
		Apathy (A)			
**	A1	helps out on the ward	76% (19%)	70% (18%)	47% (63%)
**	A2 #	occupied in useful activity	74% (33%)	56% (34%)	39% (33%)
**	A3 #	socializes with other patients	74% (40%)	51% (27%)	39% (33%)
**	A4 #	helps other patients without being asked	75% (26%)	66% (23%)	43% (51%)
*	A5	needs supervision outdoors	67% (24%)	57% (52%)	46% (24%)
**	A6 #	never starts conversations	68% (42%)	50% (31%)	44% (27%)
**	A7 #	privileges to leave the ward	- (0%)	57% (99%)	0% (1%)

item is also part of the Dependency subscale

* $0.01 < p < 0.05$ (log-rank test)

** $p < 0.01$ (log-rank test)

Multivariate prognostic models

Table 3 describes the 2 proportional hazard models for the prediction of survival time. Model 1 contains 5 BOP-items, age and gender. As expected, the mortality hazard was higher for men, and increased with age. The item "needs help when walking" was the first behavioural item selected, and had the highest rate ratio. The item "restless at night" was less significantly associated with survival in the univariate analysis ($.01 < p < .05$), but nevertheless has been selected: apparently its prognostic information was independent from the information of other items. From the Depression subscale the item "utters physical complaints" has been selected. The rate ratio of 1.1 indicates that its predictive value is limited.

Table 3. Two proportional hazard models for predicting survival, based on age, gender and the behavioural rating scale (BOP). The BOP-items resp. BOP-subscales are entered into the model by stepwise forward selection and are listed by order of entry.

variable		range	rate ratio (95% CI)	Log-like lihood
Model 1 (BOP-items)				
gender (female = 0, male = 1)		0-1	1.9 (1.5 - 2.4)	- 1964
age		50-100	1.03 (1.02 - 1.05)	
PD2	needs help when walking	0-1-2	1.4 (1.2 - 1.6)	
A2	occupied in useful activity	0-1-2	1.2 (1.0 - 1.4)	
D13	restless at night	0-1-2	1.3 (1.1 - 1.5)	
De2	utters physical complaints	0-1-2	1.1 (1.0 - 1.3)	
A3	socializes with other patients	0-1-2	1.2 (1.0 - 1.4)	
Model 2 (BOP-subscales)				
gender (female = 0, male = 1)		0-1	2.1 (1.7 - 2.7)	- 1966
age		50-100	1.04 (1.02 - 1.05)	
Physical Disability		0-6	1.16 (1.05 - 1.24)	
Apathy		0-14	1.06 (1.03 - 1.12)	
Depression		0-6	1.10 (1.02 - 1.18)	

Rate ratios express relative mortality hazards. The value for the rate ratio for the covariate age of 1.03 in Model 1 implies, for example, that at every moment after admission the risk of dying for a 90 years old person is $1.03^{10} = 1.34$ times the risk of an 80 years old person of the same gender and the same scores on the other items. If the latter person had a two year survival probability of 0.60, then the 90-year old person would have a probability of $0.60^{1.34} = 0.50$. The rate ratio of 1.9 for gender implies that at every moment the chance of dying for men is almost twice the chance for women. The rate ratio of 1.4 for the item "needs help when walking" means that the chance of dying for patients who need much help (item score 2) is 1.4 times that chance for patients who need some help (item score 1), and $1.4^2 = 2$ times that chance for those who do not need any help (item score 0). The rate ratio of 1.16 on the Physical Disability subscale in Model 2 implies that a patient with a score of 6 on that subscale has a change of dying $1.16^6 = 2.4$ times the chance for a patient with a score of 0.

Two examples show the considerable redundancy and overlap in prognostic information between the items and thus highlight the additional value of multivariate over univariate analysis. First, 25 BOP-items were significantly related to survival in the univariate analysis ($p < .05$) (Table 2), but only 5 of them have been selected. Second, of the 3 items of the Physical Disability scale - which had all highly significant differences in survival in the univariate analysis - only the item "needs help when walking" is selected in Model 1; obviously the others do not add sufficient additional prognostic information.
Model 2 contains 3 BOP-subscales, age, and gender. The rate ratios for age and gender do not differ essentially from Model 1. Of the 5 subscales with prognostic value in the univariate analyses (Table 1), the subscales Physical Disability, Apathy and Depression are selected. The Dependency and Orientation & Communication subscales do not add significantly to survival prediction once the Physical Disability subscale is selected.

Evaluation of the prognostic models

Goodness-of-fit. The two models are reliable in the sense that the model-predicted number of deaths within two year after admission corresponds well with the observed number (χ^2 test, 5 df, $p > 0.3$ for both models), see Table 4. A reference prognostic model, based on age and gender only, is added for comparison. Model 1 seems to be the easiest to implement, because the scores on a limited number of individual items are more readily available than the sumscores of the BOP-subscales. Its performance was further assessed by the split-half approach (see Methods-section). The goodness-of-fit was satisfactory, although the model underestimated the survival chances in the group with a very poor prognosis (Figure 1).

Predictive power. Once the models have been shown to be reasonably reliable, they can be evaluated for their power in individualizing survival predictions. We will focus on the prediction of two-year survival chances. A "perfect individualizing" model would give a 100% predicted survival chance to each patient of the 56% who have survived the two-year period, and a 0% predicted survival chance to each of the 44% who died. A totally non-individualizing model (the "null" model) will predict for everybody a chance that is equal to the observed 56% two-year survival rate for the total study population.
An indication of the predictive power can be obtained from Table 4. Model 1 gives a

predicted survival chance between 40% and 60% in 150 patients, and a chance of less than 20% or more than 80% in 80 patients. This model thus differentiates considerably between patients. Model 2 gives comparable results. The results for a reference model are worse. It gives a predicted survival chance between 40% and 60% in 244 patients (more than 40% of all patients), and has only a small number of patients with a prognosis of lesser than 20% or more than 80% (4 and 7 patients respectively).

Figure 1. Observed and predicted survival according to Model 1 for 4 equally sized (142) subgroups of patients with a favourable, moderate, poor and very poor prognosis according to their survival probabilities after the split-half approach on Model 1. The mean predicted 2-year survival chances for these 4 groups are 0.24 (range 0.00 - 0.39), 0.50 (range 0.39 - 0.60), 0.66 (range 0.60 - 0.73) and 0.81 (0.73 - 0.94).

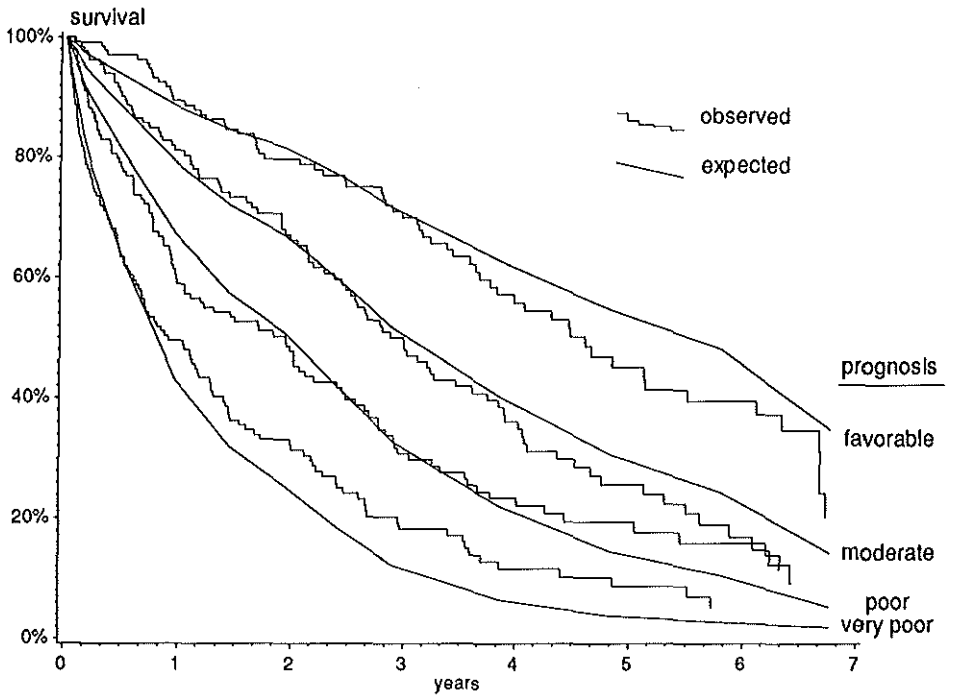
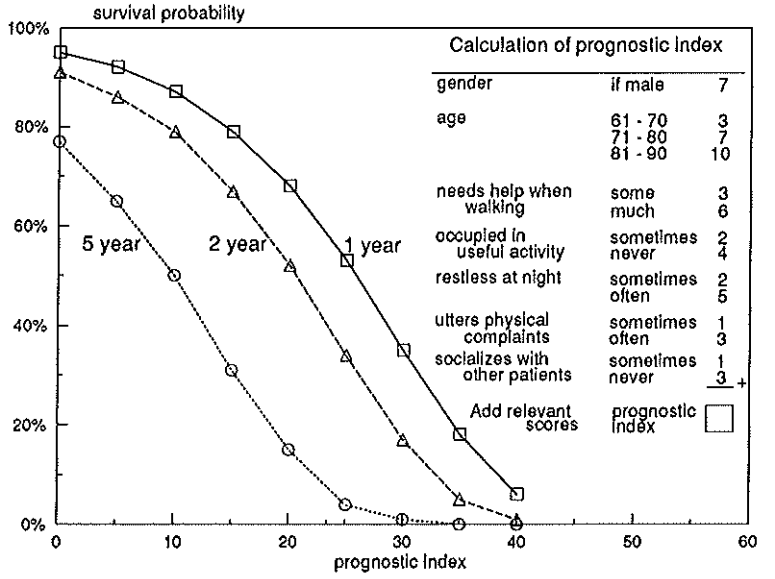


Table 4. Observed and predicted number of deaths during the first 2 year after admission according to Model 1, Model 2 and the Reference model for 5 subgroups with predicted two-year survival chances between 0 and 20%, 20 and 40%, .., 80 and 100%.

Predicted 2 year survival chance	Number of patients	Number of deaths	
		observed	expected
Model 1 (age, gender, items)			
0% - 20%	27	25	23
20% - 40%	116	66	72
40% - 60%	150	77	69
60% - 80%	223	54	60
80% - 100%	53	5	9
Model 2 (age, gender, scales)			
0% - 20%	31	24	26
20% - 40%	113	67	70
40% - 60%	150	80	69
60% - 80%	228	53	62
80% - 100%	47	3	7
Reference model (age and gender only)			
0% - 20%	4	2	2.6
20% - 40%	69	36	42
40% - 60%	244	121	108
60% - 80%	245	68	76
80% - 100%	7	0	1

Help in survival prediction. A prognostic index, and henceforth survival chances can be calculated for every person (see Methods). The average one-, two-, and five-year survival rates for the entire cohort were 72%, 56%, and 20% respectively. The prognostic index and the corresponding survival chances are easily obtainable from Figure 2 (see the legend for examples).

Figure 2. Prognostic index according to Model 2 and the predicted one-, two- and five-year survival chances. Examples. A woman of 65 years needs much assistance when walking and is sometimes "restless at night". She has favourable scores on the other 3 items. Her prognostic index is 3 + 6 + 2 = 11. In Figure 2 it can be seen that her predicted one-, two-, and five-year survival chances are 83%, 78% and 48% respectively. A man of 85 years who sometimes "utters physical complaints" and is only sometimes occupied in useful activity, and who has a score of two on the other 3 items has a prognostic index of 7 + 10 + 6 + 2 + 5 + 1 + 3 = 34, and his survival chances are only 23%, 7% and 0%.



Implications for users of the CAPE

The mean sumscores at admission on the CAPE - subscales Apathy and Communication Failure were 5.0 (±2.6) and 1.3 (±1.2) respectively. When these two scales were put into a proportional hazards model with gender and age, the Communication Failure subscale had no predictive value and the Apathy subscale had a hazard rate ratio of 1.17 for each point one scored higher (on a scale from 0 to 10). In a multivariate analyses of the 14 items, gender and age, 5 items were selected. The 7 variables and their rate ratios were: gender (1.9), age (1.03), needs help when walking (1.4), helps out on the ward (1.2), socializes with other patients (1.3), unwilling to do things asked of him (0.9), and objectionable during the night (1.3). For these 7 variables a prognostic chart similar to Figure 2 is constructed, see Table 5. For every (CAPE -) prognostic index, survival chances can be read directly from Figure 2.

Table 5. Prognostic chart for estimating survival chances, according to the results with the CAPE.

		Score
gender	if man	6
age	51 - 60	0
	61 - 70	3
	71 - 80	6
	81 - 90	9
needs help when walking	some	3
	much	7
helps out on the ward	sometimes	2
	never	4
socializes with other patients	sometimes	2
	never	5
objectionable at night	sometimes	2
	often	5
unwilling to do things asked of him	sometimes	1
	never	3
Add relevant scores:		☐
Subtract 2		☐

Use: circle relevant scores, add them to a sumscore, and subtract 2 points to get the prognostic index.

Discussion

Gender and age, and patient behaviour as measured on a behavioural rating scale (the BOP) were found to be helpful in estimating survival chances in institutionalized patients with dementia. Subscales measuring physical disability, apathy and depressive behaviour carried independent prognostic value. The first two scales were mentioned before as being of prognostic importance [14,15]. The association between the Orientation & Communication subscale and survival was only small [14] or even absent [15]. Observations in non-institutionalized patients also emphasized the prognostic value of scales measuring physical impairment [6] and impairment of ADL - activities [16]. On the item-level our results are consistent with Diesfeldt [17], who found that all items of the Physical Disability scale and 7 items of the Dependency scale were associated with one-year survival.

The 5 selected items in Model 1 are all easily interpretable, and most of them are also incorporated in other rating scales. Table 4 and Figure 1 showed that the fit of Model 1 was satisfactory. We would be very interested to see how adequately this "internally validated" model can predict survival in other nursing homes. We think our clientele is rather representative for psychogeriatric nursing homes in the Netherlands. The mean age of demented patients admitted in the Netherlands in 1986 (78 years for men and 80 years for women) was slightly lower than our clientele, and relatively more men (33%) were admitted [18]. Scores on the BOP - rating scales on dementia patients were not essentially different from figures from other nursing homes in the Netherlands, neither did the two-year survival rates [3,14,15]. Dutch nursing homes are rather comparable to American skilled-nursing facilities [19], although the availability and kind of medical care in Dutch nursing homes is different from that abroad [20].

Differences in case-mix may decrease the generalizability of the model to other settings. We therefore investigated the impact of previous residence on the results. When added to Model 1, neither the variable "coming from own house" (indicating patients with less comorbidity), nor the variable "coming from a hospital" (indicating patients with more comorbidity) had rate ratios significantly different from 1: their rate ratios were 1.1 (95% confidence interval 0.9 - 1.4) and 0.9 (0.7 - 1.1) respectively. This suggests that for an estimation of survival chances the severity of impairment (in combination with gender and age) is much more important than previous residence; this finding corroborates the possibility of using our results in other nursing homes.

Variables such as reason for admission and problems in adaptation to the sudden change in living situation are not considered in the BOP. Furthermore medical symptoms and diagnoses undoubtedly also contain prognostic information. The fact that the item "utters physical complaints" (because of physical origin or not) was selected is already an indication for this. Although comorbidity and behavioural items are mutually related - many diseases result in physical disability and dependency, and an increased severity of dementia may cause a higher vulnerability for acquiring all sorts of diseases -, comorbidity might also give independent prognostic information. For instance, the two-year survival rate for patients with a very poor prognosis according to Model 2 was 30%. Patients in this group with parkinsonism, a heart failure, or a respiratory tract infection had two-year survival rates of about 15%. This rates was 32% in the absence of these diseases. Thus, clinicians must be aware that the prognosis of the patient may be considerably worse when severe comorbidity is present.

Our results can also be of help for health planners. Patients in our nursing home had a two-year survival rate of 56%. This gives a direct indication of turnover in nursing homes. Together with demographic and epidemiological data, future demand and capacity for the current admission strategy can be assessed. It is also possible to estimate two-year survival rates, when the admission policy is changed, e.g. in such a way that only more severely demented patients are admitted. If, for instance, the mean scores on all BOP-items at admission increased with 0.5 points, the mean prognostic index according to Model 1 would have such an increase, that the expected two-year survival rate would decrease from 56% to 41%.

In conclusion, behavioural items (which in many nursing homes are assessed for other purposes anyhow) contain interesting prognostic information and can be combined in multivariate prediction models. Using these models, health care planners might be able to estimate more adequately the need of beds in the future for patients with dementia. Also, these models can support the nursing home physician in getting the best possible insight into the prognosis of a patient. The more accurate this prognosis, the more well-founded the nursing home physician can decide to perform a diagnostic evaluation or a surgical procedure, which may be of great risk and inconvenience to the patient initially, but improve the quality of life afterwards. A better life-expectancy increases the chance that the expected long-term benefit for the patient exceeds the instantaneous risk and inconvenience of the diagnostic or surgical procedure, and thus weights in favour of an active approach [21].

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Chapter 4. Comorbidity and its effect on mortality in nursing home patients with dementia.

The prevalence of dementia in the population above 65 years may be more than 10% [1]. Many of the elderly will suffer from other diseases and impairments as well (comorbidity). Patients with dementia have a reduced life expectancy, but serious comorbidity also diminishes lifespan [2,3]. Nevertheless, only few articles have reported figures about the effect of comorbidity on survival in dementia patients. In a recent article on survival in outpatients with Alzheimer dementia, "comorbid conditions" and "use of prescription drugs" were not related to survival [4]. The authors suggested that this could be due to the relatively small sample size (126 patients), and the measures used: they had only coded whether "comorbid conditions" were present or absent.

A description of prevalence rates of diseases at admission and a quantification of their influence on survival is of importance. It may contribute to the estimation of prognosis in dementia patients and it may offer a partial explanation for the large differences in survival rates between studies. For instance, hospital-based studies in patients with dementia demonstrated on average a 2-year survival rate of 40%, and outpatient-based studies a 2-year survival rate of 75% [2]. It was not possible to tell whether this difference was caused by differences in severity of dementia, in amount of comorbidity, or both.

In this article we describe the pattern of comorbidity in patients with dementia admitted to a nursing home, and we assess the effect on survival over an 8 year follow-up period. The results allow for a comorbidity-adjusted prediction of survival chances. Finally, the place of living before admission and its relation with comorbidity, severity of dementia and survival is investigated.

Patients and methods

Patients

The study population consists of 606 patients consecutively admitted between 1-1-1982 and 31-12-1988 to Stadzicht, a Dutch nursing home for demented patients. Every patient underwent a multidisciplinary examination before admission by a team, consisting of a nursing home physician, a psychologist and a social psychiatric nurse. Only patients with a diagnosis of dementia were admitted. The moment of admission depends very much on the capability and willingness of the family or other caregivers to give appropriate care. Of the 606 patients admitted, 437 were

women. Mean age at admission was 80.8 year (SD 6.8 year) for all patients, 79.6 for men (SD 7.3) and 81.3 year for women (SD 6.6). A more detailed description of the study population and the admission procedure has been presented elsewhere [3]. Follow-up data were collected until death or discharge, or until January 1st, 1990. During the follow-up period 394 persons died and 58 persons left the institution. On January 1st, 1990, 154 persons were still living in the nursing home.

Methods

Comorbidity, secondary diagnoses

Information about comorbidity was obtained from a retrospective chart review of the patients' first 6 weeks in the nursing home. This information came from four sources: the examination before admission (see Patients - section); letters about the medical history before admission from the general practitioner, specialists, and hospital admissions; a complete physical examination by the nursing home physician, a chest X-ray, an electrocardiogram, and several laboratory tests at admission; and observations during the first 6 weeks after admission, when the patients stay in a special observation department, where they are evaluated functionally, psychologically and medically. Comorbid illness diagnosed after the first 6 weeks was not included in the analysis. The diagnosis parkinsonism includes idiopathic Parkinson's disease and drug-related parkinsonism, and also the parkinsonism appearing in the later stages of dementia. Pulmonary infections include bronchitis and pneumonia. A distinction was made between pulmonary infections in stroke and in non-stroke patients, because we expected that these infections in stroke patients were more often dangerous aspiration pneumonias. Sporadic diagnoses include diseases (such as epilepsy, seizures, gastrointestinal diseases) with a prevalence of less than 5%. Incontinence was rated as present if the nursing staff considered it a persistent problem.

Diagnosis of dementia

Dementia was diagnosed according to criteria of the DSM - III - R [5]. Senile dementia of the Alzheimer's type (SDAT) was diagnosed after exclusion of other causes of dementia (e.g. hyperthyroidism, hypothyroidism, vitamin deficiencies, neurosyphilis, electrolyte abnormalities, drug-induced dementia, depression). Criteria are based on those for primary degenerative dementia in DSM - III - R. The diagnosis of

multi-infarct dementia (MID) was based on the presence of a stepwise deterioration, a fluctuating course, a patchy loss of functioning, and focal neurological symptoms and signs [6].

Severity of dementia

Scores on the Dependency - subscale of the BOP (Beoordelingsschaal voor Oudere Patiënten = Rating Scale for the Elderly), a Dutch behavioural rating scale, were used as a measure of the severity of the dementia [7,8]. Like the behavioural rating scale of the Clifton Assessment Procedure for the Elderly or the CAPE [9], the BOP is derived from the Stockton Geriatric Rating Scale [10]. The scales have 25 items in common. The subscale Dependency contains the 23 items which loaded more than 0.45 on the first factor in a factor analysis [7]. Examples of items are: "needs assistance when eating", "incontinent during the day", "does not make himself understood", "unable to find his way around the ward", "not occupied in useful activity", "urinates and defecates at inappropriate places", "needs assistance when dressing", "needs protection from falling out of bed", and "restless at night". The scale gives an overall indication of impairment on daily functioning. Each item is scored on a 0 - 2 scale depending on severity (no help, little help, much help) or frequency (never, sometimes, often). Thus subscale scores can take values between 0 (no impairment at all) and 46 (severe impairment at all 23 items). In order to investigate whether the prevalence of comorbidity depended on the severity of dementia, the cohort was divided in 2 severity - subgroups according to the score on the Dependency - subscale: 274 patients had a score below 20, and 295 patients had a score of 20 and more ([1]).

Survival analyses

Univariate analyses were performed in order to get a first impression of the influence of separate diagnoses on survival. Survival chances during follow-up were estimated by the product-limit method in order to be able to use the entire follow-up of all patients. Detailed results will be reported for the two-year survival chances.

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1 Because the BOP contains all items of the Apathy and Orientation subscale of the CAPE, scores on these 2 subscales were calculated for the convenience of readers who know the CAPE. The mean score of the 569 patients on the Apathy (range 0 - 10) and the Orientation (range 0 - 4) subscales were 5.0 (S.D. 2.6) and 1.3 (S.D. 1.2) respectively. The 274 patients with a score of less than 20 on the Dependency subscale of the BOP had mean scores of 3.3 (S.D. 2.1) and 0.6 (S.D. 0.8) on the Apathy and the Orientation subscale of the CAPE. These means were 6.6 (S.D. 1.9) and 1.9 (S.D. 1.1) for the 295 patients with a score of at least 20 on the Dependency subscale of the BOP.

Statistically significant differences in survival between subgroups were identified by the log-rank test ($p < .05$) [11,12]. Multivariate analyses were performed in order to get a deeper insight into the influence of the separate diagnoses on survival, when adjusted for the influence of age, gender, and other diagnoses. The statistical program BMDP was used to perform multivariate proportional hazards regression analyses [13]. Again survival data from the entire follow-up period were used. Age and gender were always included. Variables with additional prognostic value were selected in a stepwise forward mode. The rate ratios which result from such a model can be considered as relative risks.
The goodness-of-fit and the stability of the model was cross-validated by the split-half approach. The entire cohort was randomly split into 2 (equally sized) groups A and B. First the stepwise forward selection procedure was carried out on group A (the training sample), and the resulting model was used to predict survival chances in group B (the test sample). Subsequently, group B functioned as the training sample and the resulting model was used to predict survival chances in group A. So for every patient survival chances were predicted by a model which did not use his data for its construction. The fit between observed and predicted numbers of deaths during the first two year after admission was assessed with chi-square goodness-of-fit statistics.

Results

Comorbidity and survival

Univariate analyses

Several diagnoses were associated with a decrease in survival (Table 1). Men with parkinsonism, pulmonary infection, anemia, and malignancies had less than the average two-year survival rate of 39%. In women, myocardial infarction, heart failure, atrial fibrillation, parkinsonism, diabetes mellitus, pulmonary infection, pressure sores, malignancies, and a previous hip operation all considerably decreased survival. Survival in stroke and hypertension patients was not statistically significant decreased. Survival decreases steadily with an increasing number of diagnoses from two-year survival rates of 48% for men and 80% for women without diagnoses to rates of 25% resp. 27% in men and women with 3 or more diagnoses. Myocardial infarction, heart failure, diabetes mellitus, and pressure sores affected survival more in women than in men: the better survival in women disappears when one of these diseases is present.

Table 1. Two year survival rates in dementia patients for various types of comorbidity.

	Two-year survival rate (relative frequency of the comorbid condition)			
	Men (N = 169)		Women (N = 437)	
All patients	39% *(100%)*		60% *(100%)*	
Diagnoses				
previous myocardial infarction	33% *(9%)*		26% *(5%)*	*
heart failure	80% *(7%)*		20% *(8%)*	*
atrial fibrillation	19% *(12%)*		37% *(8%)*	*
hypertension	53% *(8%)*		54% *(11%)*	
previous stroke	39% *(20%)*		56% *(12%)*	
previous TIA	26% *(10%)*		43% *(7%)*	
parkinsonism	18% *(19%)*	*	41% *(11%)*	*
chronic lung disease	38% *(18%)*		51% *(5%)*	
diabetes mellitus	68% *(6%)*		34% *(12%)*	*
hip fracture	20% *(3%)*		50% *(9%)*	
pulmonary infection	16% *(15%)*	*	36% *(8%)*	*
urinary tract infection	35% *(14%)*		56% *(17%)*	
anaemia	0% *(5%)*	*	34% *(5%)*	
pressure sores	36% *(7%)*		28% *(7%)*	*
malignancies	11% *(5%)*	*	40% *(5%)*	*
previous hip operation	55% *(18%)*		58% *(29%)*	
Number of diseases [a]				
no diagnosis	48% *(21%)*	*	80% *(29%)*	*
1 diagnosis	42% *(28%)*		66% *(30%)*	
2 diagnoses	39% *(31%)*		54% *(22%)*	
3 or more diagnoses	25% *(20%)*		27% *(19%)*	
sporadic diagnoses	37% *(27%)*		47% *(37%)*	*
Chronic impairment				
hearing impairment	17% *(17%)*	*	51% *(15%)*	
visual impairment	25% *(22%)*		50% *(27%)*	*
fecal incontinence	39% *(25%)*		57% *(25%)*	
urinary incontinence	34% *(50%)*		52% *(44%)*	*

[a] number of diseases from the above 16 diagnoses

* $p < .05$, log-rank test

Multivariate analyses

The multivariate model consisted of age, gender and the 10 comorbid variables which were selected in the stepwise-forward process (Table 2). "Pulmonary infection and stroke" was selected first, followed by malignancy and atrial fibrillation. The results confirmed the univariate analyses: pulmonary infection, parkinsonism, malignancies and atrial fibrillation were significantly associated with increased mortality. Having any of these diagnoses doubled the mortality rate. The rate ratio of 1.7 for gender means that the mortality rate for men is almost twice the rate for women. The rate ratio of 1.04 for age means that the mortality rate increases by 4% for each year of age above 50 on admission.

Table 2. A multivariate model for predicting survival in Dutch Nursing Home patients with dementia.

variables	regression coefficient	rate ratio (95% confidence interval)
gender [a]	0.52	1.7 *(1.4-2.1)*
age at admission	0.038	1.04 *(1.02-1.06)*
diagnoses [b]		
pulmonary infection and stroke	2.79	16.4 *(7.4-43.8)*
pulmonary infection, no stroke	0.57	1.8 *(1.3-2.4)*
parkinsonism	0.62	1.9 *(1.4-2.5)*
atrial fibrillation	0.68	2.0 *(1.4-2.7)*
heart failure	0.53	1.7 *(1.2-2.4)*
diabetes mellitus	0.45	1.6 *(1.2-2.1)*
pressure sores	0.58	1.8 *(1.2-2.6)*
urinary incontinence	0.28	1.3 *(1.1-1.6)*
visual problems	0.23	1.3 *(1.0-1.6)*
malignancy	0.77	2.2 *(1.4-3.3)*

a female = 0, male = 1

b absent = 0, present = 1

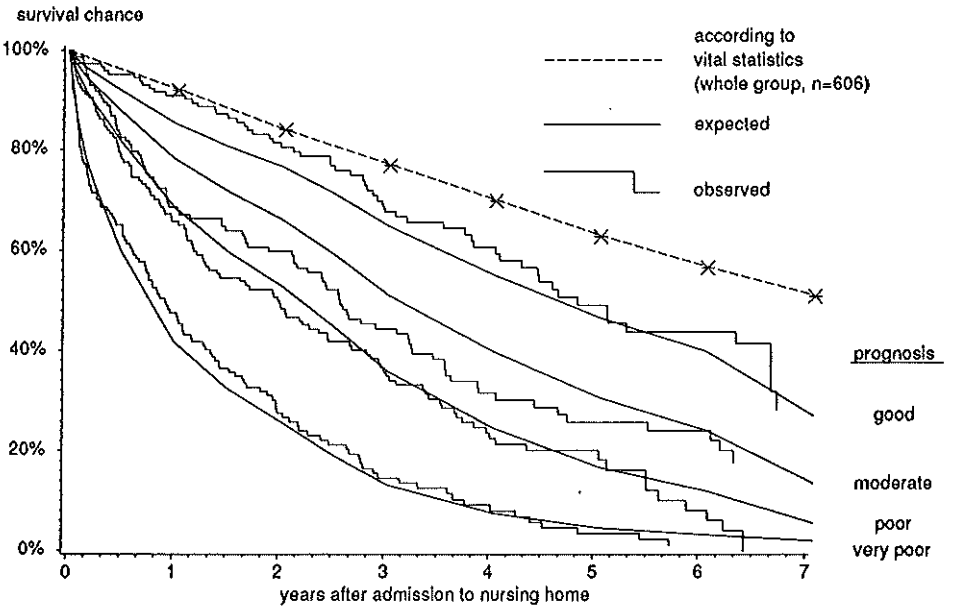
The rate ratio of 16.4 (CI 7.4 - 36.3) for "pulmonary infection and a previous stroke" was particularly high. Pulmonary infection in patients without a previous stroke carried a rate ratio of 1.8 (see Table 2). Three other diagnoses (heart failure, diabetes mellitus, and pressure sores) had a rate ratio of about 1.5. Urinary incontinence and visual problems only gave an about 25% increased rate, but they were nevertheless selected because of their high prevalence. Several conditions that were statistically significant in the univariate analyses of Table 1, were not selected. Hearing impair-

ment and previous hip operation did not add sufficient independent prognostic information once age and gender were forced into the model. For anemia this was the case after "pulmonary infection and a previous stroke" was selected.

Model evaluation

For all 606 patients two-year survival chances were calculated from the results of the split-half approach. These chances were used for classifying each patient in one of 4 (equally-sized) prognostic groups (see Figure 1). Their predicted 2-year survival chances were 76%, 66%, 52%, and 25% respectively. The observed survival curves resembled the expected ones, but there was an overestimation of survival in the groups with a moderate and with a poor prognosis, and an underestimation of survival in the group with a good prognosis.

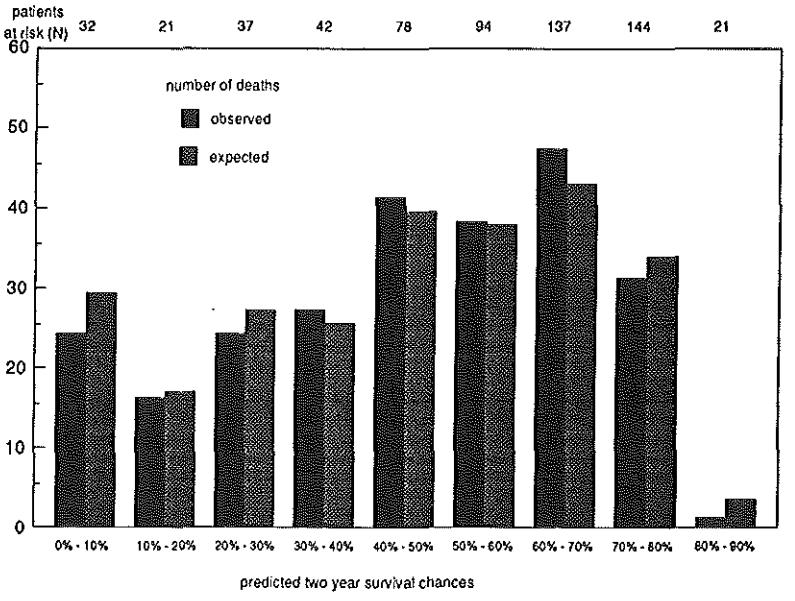
Figure 1. Observed and expected survival according to the model for subgroups of patients with a good, moderate, poor and very poor prognosis according to their predicted survival chances on the model, obtained from the cross-validation with the split-half approach. The asterisks represent the expected survival chances for the entire cohort according to the Dutch national vital statistics.



The statistical assessment of the goodness-of-fit is illustrated in Figure 2. For this purpose the patients were divided in 9 groups with predicted two-year survival chances between 0% - 10%, 10% - 20%, ... , and 80 - 90% respectively. Nobody had a predicted survival chance above 90%. For every group the observed number of deaths closely fits the expected number ($\chi^2 = 3.6$, 9 df, $p > 0.9$). For instance, 24 of the 32 patients with a predicted survival chance below 10% died, while 29.1 deaths were expected. Of the 21 patients with a predicted survival chance between 80% and 90%, 1 patient died, while 3.3 deaths were expected according to the model.

Figure 2 also gives an impression of the predictive power, i.e. the power to identify patients with a very good or a very poor prognosis: the model gives e.g. a predicted 2-year survival chance of less than 10% to 32 patients, and a chance of more than 80% to 21 patients. As a contrast, a model based on gender and age only identifies no patient at all with a predicted 2 year-survival chance of less than 10%, and only 6 patients with a chance of more than 80%.

Figure 2. Observed and expected number of deaths within two year after admission according to the predicted two year survival chances of the model. The predicted two-year survival chances are the chances obtained with the cross-validation with the split-half approach.



Comorbidity, severity of dementia, and survival.
In order to explore whether the prevalence of comorbidity and the impact on survival depended on severity of dementia, two severity subgroups were constructed (see Methods - section). From the diagnoses selected in the model, pulmonary infection, parkinsonism, pressure sores, urinary incontinence and visual problems were more frequently present in the group of more severely demented patients ($p < .05$). The other diagnoses of the model did not show statistical significant differences in prevalence rates.
The relatively less dependent patients had a two-year survival rate of 72%. For the more dependent patients this rate was 42%. For both groups survival decreased evidently with the number of diagnoses: from 86% resp. 55% if there is no comorbidity to 57% resp. 32% when at least 2 diagnoses are present.
The influence of comorbidity on survival seemed greater for women than for men: two-year survival rates for relatively less and the relatively more dependent women with no comorbidity were much higher (90% and 63%) than these of their male counterparts (66% and 33%). These differences were much smaller when there were 2 or more diagnoses present (60% and 35% vs. 50% and 28%).

Place of living before admission
From the 569 patients with Dependency scores, 241 patients came from their own home, 108 patients came from a hospital, 106 patients from a home for the aged, 97 patients from another nursing home, and 17 patients from other places. Patients coming from their own home had the lowest mean number of diagnoses (1.2, SD 1.3) and the highest two-year survival rate (60%), and those coming from a hospital the highest mean number of diagnoses (2.1, SD 1.5) and the lowest two-year survival rate (51%). The mean Dependency score for hospital patients (20.9, SD 8.9) was significantly higher than that score for patients coming from home (18.0, SD 9.0). For both groups survival decreased evidently with the number of diagnoses: from 86% resp. 55% if there is no comorbidity to 57% resp. 32% when at least 2 diagnoses are present.
Stratified for severity of dependency and number of diseases, the survival rates in hospital patients were not significantly lower than in patients coming from home. For instance, the two-year survival rates for the relatively less demented patients with at least two diseases from Table 1, coming from the own house (N=52) and coming from the hospital were 61% and 52% respectively. These rates were 24%

(N=41) and 40% (N=43) respectively for the more severely demented patients. This suggests that the diseases in hospital patients were not more severe than in patients coming from home.
When the variables "coming from hospital" and "coming from own home" were added to the multivariate model (Table 2), neither of them had a significant independent influence on survival: the rate ratios were 1.2 (95% CI 0.9 - 1.5) and 0.95 (95% CI 0.8 - 1.2) respectively.

Discussion

Univariate and multivariate analyses confirmed and quantified the association between comorbidity and reduced survival in dementia patients after admission to a nursing home. Several conditions diagnosed at admission evidently increased the mortality risk during 8 years of follow up. The relatively more severely demented patients had more comorbid illness than patients in whom the dementia was less severe, but the impact of comorbid illness on survival did not differ between the two severity clusters.

Comorbidity and survival

A pulmonary infection clearly diminished survival chances in patients with a stroke. Eight out of the nine patients in our study with both diagnoses died within 2 months. Stroke is frequently mentioned as an important immediate cause of death in dementia patients [15-21]. In our study, stroke (without a pulmonary infection) did not affect survival, because the majority of the strokes in our cohort were old strokes, and only a few patients had a stroke just before or just after admission. The same is true for myocardial infarction, and therefore its impact on mortality is also less than might be expected. Both diagnoses should be regarded as an indicator of vascular disease. Hypertension did not influence survival. This is in accordance with Mattilla who found that high blood pressure may not be associated with excess mortality in the very old [22]. The relation between atrial fibrillation and poor survival in dementia patients has been described before [23].
We do not know why myocardial infarction, heart failure, pressure sores and diabetes mellitus had a greater impact on survival in women than in men. It may be a chance finding. The increased mortality in patients with parkinsonism is in accordance with general opinion. The increased mortality in case of pressure sores confirms the results of an earlier study [24]. Probably, pressure sores indicate that the patient is in a generally deteriorated condition.

Performing multivariate analyses can be associated with many problems such as interaction between variables on their effect on mortality, and non-proportional hazards [25]. For instance, the rate ratios for pressure sores and pulmonary infection were not entirely accurate and changed over time: during the first half year the risk of dying for patients with a pulmonary infection was 2.5 times the risk for patients without, and afterwards this relative risk was only 1.4. For pressure sores the relative risk was 3.2 during the first half year, and this risk was 1 afterwards. A significant interaction between age and comorbidity occurred only with a malignancy: the influence on mortality rates was larger in younger patients and a 5% adjustment for each year the patient was older, was needed. The rate ratio of a malignancy was 2.5 for patients of 80 years old, and for people of e.g. 70 and 90 years this ratio was 4.2 and 1.5 respectively.

Model evaluation

The goodness-of-fit of the comorbidity model was satisfactory (Figure 1 and Figure 2). The model carries considerable prognostic information: Figure 2 showed groups of patients with a very favourable, and with a very poor prognosis. A model based only on gender and age was hardly able to identify such patients. Furthermore it can be seen in Figure 1, that the median survival time after admission is more than 4 years for the quarter of patients with the most favourable prognosis, and only one year for the quarter with the poorest prognosis.

The comorbidity model was better in identifying patients with a very poor prognosis than a model based on behavioural items which does not explicitly accounts for serious comorbidity [26]. The behavioural prognostic model, on the other hand, was better able to identify the patients with a very favourable prognosis, probably because it can distinguish between the relatively mildly and the more severely demented patients.

Comorbidity, severity of dementia, and survival

The hypothesis that especially *the dementia* is associated with high mortality [27], and that the presence of physical illness in dementia patients is not sufficient to account for their shortened life span [28], is confirmed in our study: men and women with "no diagnoses" had two-year survival rates of 44% and 73% (Table 1). 80-Year old men and women in the general population, which includes patients with multiple diseases, have rates of about 80% and 90%. Figure 1 indicates that the survival chances

for the entire cohort according to the vital statistics (dotted line) are higher than those for the group of patients with the most favourable prognosis according to the comorbidity model.
We expected that the prevalence of comorbidity would be higher in the relatively more severely demented patients, because they are on average more often bedbound and apathetic, and they are more often in a poor physical condition. This hypothesis was confirmed. We also expected that the lethality of comorbidity would be higher in the relatively more severely demented patients, because they often can not describe symptoms and complaints adequately, they will more often refuse water and food when they feel ill, and they are more often in a poor physical condition. This hypothesis was not confirmed: the decrease in survival rates with the increase of number of diagnoses were comparable for the two severity - subgroups.
Because relatively many of our patients suffered from severe cognitive decline according to the Global Deterioration Scale [29], the generalizability is probably not allowed for only slightly demented patients. It would be interesting to investigate whether the finding that the lethality of comorbidity was independent from severity of dementia can be extrapolated to the demented patients who still live in the community. Place of living did not contain independent prognostic information in the multivariate model, implying that the model does not depend on case-mix.
In conclusion, this study confirmed that both dementia and comorbidity had a considerable life-shortening effect on dementia patients. The influence of comorbidity on mortality seemed to be independent from the severity of the dementia.
In this study we analyzed data on comorbidity at admission, and not the influence of medical complications afterwards. The data were collected retrospectively, and this made it impossible to take the severity or the stage of the comorbid conditions reliably into account. Nevertheless we think that this study is an important step towards a detailed quantitative analysis of the influence of comorbidity on mortality in dementia patients. Eventually this could lead to a comorbidity index which indicates how much the survival chances of a patient increases as a result of having one or more diagnoses. Such an index might also be used to investigate the influence of comorbidity on, for instance, the progression of the dementia.
Its clinical use could be the following: if a patient is severely demented, major surgery is hardly ever justifiable. On the other hand, surgery can considerably improve the quality-of-life in a relatively mildly demented patient, and a nihilistic approach might neither be justifiable. Especially in a patient in whom there is doubt about the usefulness of surgery, knowledge about the life-expectancy can play a role in decision making. For example, patients with senile cataract or osteoarthritis of the hip

will be readier candidated for surgery if they have a relatively long life expectancy. The instantaneous risk and inconvenience of surgery then becomes relatively less important, because the patient can longer benefit from a lens implantation or a hip replacement. The clinician's estimation of life expectancy is normally largely based on clinical experience and intuition. Unfortunately, in the absence of systematic observations this can lead to incorrect, or at least to suboptimal predictions [30]. Systematic observation of survival time data - such as collected in our study - can increase the validity of predictions. The subsequent interpretation of the prediction, and the judgment of its value in view of other factors which play a role in the decision whether to operate or not, remains the responsibility of the clinician.

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Appendix

By multiplying the patient's values on the selected variables with the regression coefficients of the variables in the model (see Table 2), and adding them to a sumscore, for every patient a comorbidity index CI can be calculated for prognostic purposes. For instance, the predicted two-year survival can be estimated according to the equation $S_i(2) = 0.56^{\exp(CI_i - 3.8)}$, where $S_i(2)$ is the chance for an individual i for at least surviving till two years, and 0.56 is the mean two-years survival chance, CI_i is the comorbidity index for an individual i, and 3.8 is the mean CI for the 606 patients. For instance, a man of 85 years old at admission with atrial fibrillation and a heart failure has a CI of 0.52 + (85 * 0.038) + 0.68 + 0.53 = 4.96. His $S_i(2) = 0.56^{\exp(4.96 - 3.8)} = 0.56^{3.2} = 0.16$. A women of 75 years old at admission with only diabetes mellitus has a CI of (75 + 0.038) + 0.45 = 3.3. Her $S_i(2) = 0.56^{\exp(3.3 - 3.8)} = 0.56^{0.6} = 0.70$.

For the calculation of survival chances for other periods, the value of 0.56 should be replaced as follows: 1 year: 0.71; 3 years: 0.38; 5 years: 0.19. The coefficient CI does not change for other follow-up periods.

Chapter 5. A model for the prediction of survival chances in nursing home patients with dementia.

Dementia leads in most cases to irreversible cognitive and physical decline. Many patients with dementia become incapacitated and dependent, and have to be admitted to a nursing home. In the Netherlands about 350 nursing homes have special facilities for the long-term care of these patients. Information about the prognosis of dementia is relevant for getting insight into the course of the disease, is important for health care planners, and is crucial for clinicians when they want to inform the patients and their relatives, or when they have to make decisions about diagnostic evaluation or treatment.

Earlier studies towards prognosis in dementia patients suggested that patient characteristics such as gender [1,2,3], age [2,4,5], and severity of dementia [3,4,6-8] are associated with survival.[9] These findings were confirmed in our follow-up study of survival in 606 dementia patients admitted to a nursing home [10,11]. Furthermore we found that dementia itself was the major cause for the excess mortality in these patients [10]. Analyses using a combination of behavioural items [11] or of comorbid conditions [12] resulted in more powerful prediction models than could be obtained with univariate analyses.

In this article we will proceed from these earlier partial analyses [11,12], and derive a prediction model, which combines the prognostic information from age, gender, behavioural problems, and comorbidity. The results are used for the design of an easily applicable prognostic chart for estimating survival chances in individual patient profiles.

Patients & methods

Patients

606 Patients were admitted between 1-1-1982 and 31-12-1988 to Stadzicht in Rotterdam, a nursing home for demented patients. Follow up data were collected until death or discharge, or until January 1st, 1990. During follow up 394 persons died and 58 persons left the nursing home. At January 1st, 1990, 154 persons were still alive. The results are based on 569 patients in whom a Dutch behavioural rating scale was completed at about 6 weeks after admission (see below). Seventeen patients died before this scale could be completed. The scale was not completed in 20 (3%) of the other patients. The remaining patients have a mean age of 80.8 years (SD

6.8). The mean age is 81.4 years (SD 6.4) for women (n=410), and 79.4 year (SD 7.4) for men (n=159). The age range was 52 to 95 years. Four-hundred seventy-seven patients were diagnosed as suffering from Senile Dementia of the Alzheimer's Type (370 women and 107 men), 83 patients had a clinical diagnosis of Multi-Infarct Dementia (36 women and 47 men). For 9 patients the type of dementia was not established within the observation period of 6 weeks. A more detailed description of the population under study has been given elsewhere[10,11].

Diagnosis of dementia

Dementia was diagnosed according to criteria of the DSM - III - R [13]. For this purpose every patient receives a medical and psychological examination, and clinical laboratory evaluation [10]. The diagnosis of possible Senile Dementia of the Alzheimer's type (SDAT) was made according to McKhann [14]. The diagnosis of multi-infarct dementia (MID) was based on the presence of a stepwise deterioration, a fluctuating course, a patchy loss of functioning, and focal neurological symptoms and signs [15]. CT-scanning of the brain was not performed routinely.

Severity of dementia

The *BOP* (Beoordelingsschaal voor Oudere Patiënten) is a behavioural rating scale for the elderly. The scale contains 35 items and is used in many nursing homes in the Netherlands [16,17]. Like the behavioural scale of the CAPE [18], it is derived from the Stockton Geriatric Rating Scale [19]. A factor analysis resulted in 6 subscales: Dependency, Aggressiveness, Physical Disability, Depression, Orientation & Communication, and Apathy [16]. The subscale Dependency was used for the assessment of severity of dementia.

Nurses who take care of the patient score each item on a 0 - 2 scale with higher scores indicating more severe or frequent disability. In our analyses we used the BOP-scores measured about 6 weeks after admission, at the end of the observation period. In order to assess whether there was a relation between the prevalence and mortality of comorbid conditions with severity of dementia, patients with a score between 0 and 19 on the Dependency-scale were considered as (at most) "moderately dependent", and those with a score between 20 and 46 as "severely dependent".

Comorbidity, secondary diagnoses

Information about comorbidity was obtained by retrospective chart review. In this article, only the prognostic value of diseases selected in our earlier analyses, was assessed [12]. Heart failure, atrial fibrillation, parkinsonism, diabetes mellitus, pulmonary infection, pressure sores, malignancy, and visual problems were all diagnosed or confirmed by the nursing home physician during the observation period, which was defined as the first 6 weeks in the nursing home. Stroke must be read as history of stroke. Urinary incontinence was rated as present if the nursing staff had defined it as a persistent problem. The diagnosis parkinsonism includes idiopathic Parkinson's disease and drug-related parkinsonism, and also the parkinsonism appearing in the later stages of the dementia. Pulmonary infections include pneumonia and bronchitis. Comorbid illness diagnosed after the observation period was not included in the analyses.

Methods

Survival is calculated from time at admission and estimated by the product-limit method. Significant differences in survival between subgroups are identified by the log-rank test [20]. Multivariate analysis of prognostic factors is carried out using a proportional hazards regression model [21], with a stepwise forward selection of variables according to the maximum partial likelihood method [22]. Variables are entered or removed on the basis of tail probabilities ($p < .10$ and $p > .15$ respectively) from a likelihood ratio test [22]. For every patient a prognostic score PS is calculated by multiplying the patient's values on the selected variables with ten times the regression coefficients of the variables in the model, and adding them to a sumscore. Besides that, prognostic subscores were calculated for the combination of age and gender ($P_{a,g}$), the behavioural items (P_{bop}), and the comorbid conditions (P_{com}). Pearson correlation coefficients between these subscores were calculated.

When using a proportional hazards model, for each patient the *hazard* of dying at time t is estimated by the equation $\lambda_i(t) = \lambda_{mean}(t) * \exp(PS_i - PS_{mean})$, where $\lambda_i(t)$ is the hazard of dying for an individual i at time t, $\lambda_{mean}(t)$ is the hazard of dying for someone with a mean score on all selected variables, PS_i is the prognostic score for an individual i, and PS_{mean} is the mean prognostic score of the 569 patients.

It can be calculated that for each patient *survival* is estimated according to the equation $S_i(t) = S_{mean}(t)^{\exp(PS_i - PS_{mean})}$, where $S_i(t)$is the chance for an individual i at least surviving till time t, and $S_{mean}(t)$ is the chance at least surviving time t for someone with a mean prognostic index.

The goodness-of-fit of the model was assessed by the permutated split-half method by randomly dividing the entire cohort into 2 equally sized halves. The forward stepwise selection procedure was performed on one halve, and the results were used to predict survival chances in the other. The same process was repeated the other way round so that every patient was a test case once. Subsequently the patients were divided in 10 groups according to their predicted survival chance, and the observed number of deaths during the first two year after admission was compared with the expected number of deaths (chi-square test).
If the goodness-of-fit of the model is satisfactory, the predictive power can be assessed. As a measure for this we will use the relative standard deviation, i.e. the ratio between the standard deviation of the 606 predicted two-year survival chances of the model, and the standard deviation of a perfect model, which identifies with absolute certainty whether a patient will survive 2 year or not: i.e. patients who are going to die, get a 0% chance, and survivors a 100% chance. Because 55% of the patients survived 2 years, the standard deviation of this perfect model is $\sqrt{0.55*(100-55)^2+0.45*(0-55)^2} = 49.5$. The predictive power of the perfect model is then by definition 100%. This can be contrasted with the 0% predictive power of the "uninformative" system, which indiscriminately gives 55% survival chance predictions for all patients.

Results

Comorbidity and severity of dementia
Table 1 shows two-year survival rates for the 10 diagnoses which in previous analyses were most related with survival [12]. Except for heart failure and atrial fibrillation, all diagnoses were more prevalent in patients with severe dependency. Patients with moderate dependency had on average 1.0 (SD 1.0) of the diagnoses, and patients with severe dependency 1.9 (SD 1.1). Severity of dependency has considerable predictive value (a 2-year survival rate of 72% and 42% for moderately and severely dependent patients respectively; log-rank test, $p < .001$), but comorbidity gave additional prognostic information: most diagnoses had 2-year survival rates below 72% and 42% respectively, and for both severity groups the 2-year survival rates decreased with the number of diagnoses. The mortality in patients with 3 or more diagnoses was about 3 times higher than the mortality in patients with no diagnosis,

both for the moderately (55% / 21%), and for the severely dependent patients (83% / 27%). This suggests that dependency and comorbidity contribute independently to mortality.

Table 1. Comorbidity related two-year survival rates for dementia patients with moderate or severe dependency.

	two-year survival rate (relative frequency of disease or symptom)			
disease	moderate dependency (N = 274)		severe dependency (N = 295)	
All patients	72%	*(100%)*	42%	*(100%)*
heart failure	47%	*(8%)*	15%	*(7%)*
atrial fibrillation	47%	*(9%)*	14%	*(8%)*
parkinsonism	77%	*(6%)*	24%	*(22%)*
diabetes mellitus	62%	*(9%)*	31%	*(11%)*
pulmonary infection	53%	*(7%)*	17%	*(12%)*
previous stroke	56%	*(11%)*	51%	*(16%)*
pressure sores	100%	*(1%)*	29%	*(10%)*
malignancy	19%	*(3%)*	32%	*(6%)*
visual problems	64%	*(22%)*	31%	*(29%)*
urinary incontinence	71%	*(25%)*	41%	*(67%)*
Number of the 10 diagnoses				
0	79%	*(37%)*	73%	*(9%)*
1	80%	*(36%)*	49%	*(30%)*
2	57%	*(16%)*	47%	*(34%)*
3 or more	45%	*(11%)*	17%	*(27%)*

Multivariate analyses

In assessing the joint prognostic value of several variables we used proportional hazard models with forward stepwise selection. The variables considered were gender, age, behavioural problems, type of dementia and comorbidity. Gender and age were forced into the model (see Table 2). They remained significant after the selection of other predictive variables. The risk of dying for men was 1.8 times the risk for women. The rate ratio of 1.03 for age means that for every year older at admission the risk of dying increases with 3%.

Table 2. Rate ratios of the prognostic model for dementia nursing home patients with gender, age, and selected comorbidity and behavioural items as independent variables.

variable	rate ratio (95% confidence interval)	sequence of selection
gender (female = 0, male = 1)	1.8 *(1.3 - 2.1)*	forced
age	1.03 *(1.02 - 1.05)*	forced
needs help when walking	1.3 *(1.2 - 1.6)*	2
occupied in useful activity	1.3 *(1.1 - 1.5)*	4
restless at night	1.3 *(1.1 - 1.5)*	7
utters physical complaints	1.2 *(1.1 - 1.4)*	9
pulmonary infection, and stroke (1.5%)	34.1 *(14.6 - 79.8)*	1
pulmonary infection, no stroke (8%)	1.5 *(1.1 - 2.2)*	11
atrial fibrillation (9%)	2.2 *(1.6 - 3.2)*	3
malignancy (5%)	2.1 *(1.4 - 3.3)*	5
heart failure (8%)	1.8 *(1.2 - 2.6)*	6
diabetes mellitus (10%)	1.6 *(1.2 - 2.3)*	8
parkinsonism (14%)	1.6 *(1.2 - 2.2)*	10

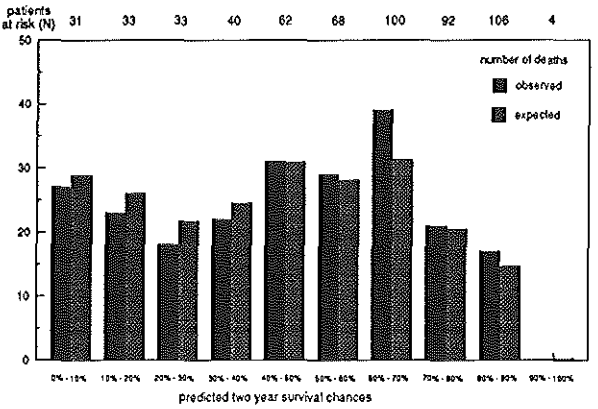
The variable "needs help when walking" was the first behavioural item selected. Patients who need much help have 1.3 times the chance of dying of patients who need some help, and $1.3^2 = 1.7$ times the chance of those who need no help. The other three behavioural items selected also had rate ratios of about 1.3.

The comorbidity variable describing the combination of pulmonary infection with a stroke had the highest rate ratio. Adjusted for the other variables, a pulmonary infection in patients with a stroke gives a risk 34 times the risk of dying compared to patients with neither of the two diagnoses. Patients with a pulmonary infection but

no stroke run 1.5 times the risk of dying of patients with neither of the 2 diagnoses. The rate ratios of the other diagnoses selected in the model (heart failure, malignancies, diabetes mellitus, atrial fibrillation, and parkinsonism) varied between 1.6 and 2.2. Pressure sores, visual problems, and urinary incontinence were not selected in the model. MID-patients had no higher risk of dying than SDAT-patients.
There were statistically significant ($p < .001$), but small correlations between the three subscores of the prognostic model ($P_{a,g}$, P_{bop}, and P_{com}, see Methods section), suggesting that the 3 parts of the model (age & gender, behavioural items, and comorbidity) contain rather independent prognostic information. The Pearson correlation coefficient between the subscores P_{bop} and P_{com} was 0.17. Between the subscores $P_{a,g}$ and P_{bop} this coefficient was 0.16, and between $P_{a,g}$ and P_{com} 0.11.

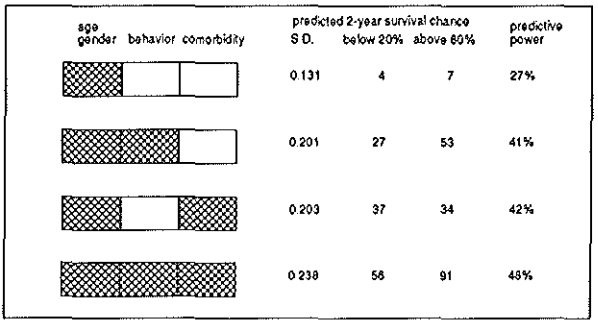
Goodness-of-fit
As explained in the Methods-section, the model was cross-validated according to the permutated split-half method. The goodness-of-fit was satisfactory: when patients were divided in 10 groups according to their predicted survival chances (see Figure 1), the observed number of deaths in these groups in a two-year period closely resembled the expected number (chi-square = 1.1, 10 df., $p > .9$). For instance, 27 of the 31 patients with a predicted survival chance below 10% died, whereas 29 deaths were expected. Of the 106 patients with a predicted chance between 80% and 90% 17 patients died, whereas 15 deaths were expected.
Predictive power.
The model identified many patients with a very poor or with a very favourable prognosis. 64 Patients (11%) had a predicted two-year survival chance below 20%, and 110 patients (19%) of above 80%. Generally spoken, the more patients fall in these extreme categories, the higher the predictive power. This model had a predictive power of 48%, when compared with a perfect model (see Methods-section).

Figure 1. Observed and expected number of deaths in a two-year period for dementia patients, divided in 10 groups according to their predicted survival chances of the model, obtained with the cross-validation by the split-half approach.



The predictive power is compared with models with limited information in Figure 2. The number of patients with chances below 20% or above 80% slightly differ from these in Figure 1 because the permutated split-half method was not used, but the proportional hazard analysis was performed on all 569 patients together.

Figure 2. Predictive properties of proportional hazard models based on an increasing amount of prognostic information. Predicted survival-chances are based on calculations of the entire cohort of 569 patients.



The most striking finding of this model was the large number of patients with a predicted two-year survival chance above 80%: it nearly doubled the number in the behavioural model because it took serious comorbidity into account [11], and it more then doubled the number of patients in the comorbidity model because it took the severity of dementia into account [12]. This finding suggests that comorbidity and behavioural items contain much independent predictive information. Compared with the other 2 models there were also much more patients with a very poor prognosis. A model with only gender and age predicted a two-year survival below 20% in only 4 patients (men of at least 93 years old), and a chance above 80% in 7 patients (women younger than 65 years).

Use of the prognostic model in practice

As explained in the Methods-section, the model estimates survival chances in individualized patient profiles from their value on a prognostic score. We have designed a prognostic chart which enables the physician to calculate this score in an easy way, see Table 3. The predicted survival chance is shown in Figure 3. The Appendix gives two selected patients with their characteristics and their prognostic score.

Figure 3. Predicted survival chances for several values of the prognostic index.

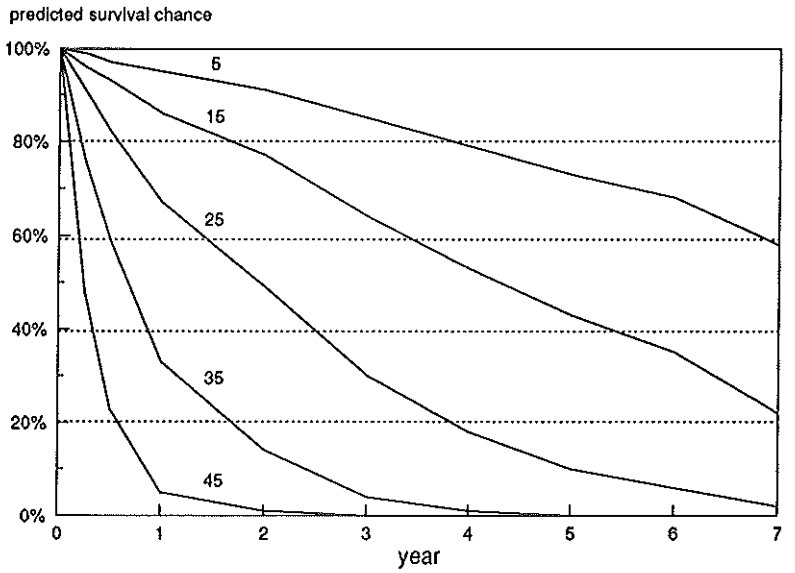


Table 3. Prognostic scoring chart for use in predicting survival chances for nursing home patients with dementia. The sumscore can easily be obtained by circling relevant scores and adding them to the sumscore.

		Score
gender	if man	6
age	age 55 - 64	3
	age 65 - 74	6
	age 75 - 84	19
	age ≥ 85	12
pulmonary infection and stroke	if present	35
pulm.inf. without stroke	if present	4
atrial fibrillation	if present	8
parkinsonism	if present	5
heart failure	if present	6
malignancy	if present	8
diabetes mellitus	if present	5
needs help when walking	some	3
(no - some - much)	much	6
occupied in useful activity	sometimes	3
(often - sometimes - never)	never	5
restless at night	sometimes	2
(often - sometimes - never)	often	5
utters physical complaints	sometimes	2
(often - sometimes - never)	often	4
Add relevant scores:	Prognostic score:	

Discussion

This analysis showed that several kinds of patient characteristics are relevant for a quantitative estimation of prognosis in demented patients admitted to a nursing home. Gender and age, medical diagnoses, and behavioural items describing difficulties in daily life all had independent value in predicting survival.

As far as we know, this is the first large-scale study with a multivariate, quantitative analysis of survival in dementia patients followed by an estimate of individualized prognosis. Two other studies reported results of multivariate analyses. Hier found that lower blood pressure and higher scores on a psychological test (Block Designs) were the predictors most associated with longer survival in 61 patients with Alzheimer's disease [23]. More years of education, female gender, and higher scores on two other psychological tests were associated with longer survival in 34 patients with multi-infarct dementia. The small number of patients in the 2 groups might have prohibited that other variables were identified as predictors. The cohort of Martin was much larger (202 demented and 202 non-demented patients [6], but unfortunately he reported only the results of a multivariate analysis on all 404 patients: dementia and physical impairment (measured with the OARS, a behavioural rating scale) were the 2 significant predictors.

The analyses showed that *comorbidity* had a considerable impact on survival (see also [12]), which seemed not to depend on the severity of the dementia. In other words, while severely demented patients may have a greater risk of getting a disease, its lethality is not greater than in moderately demented patients. Although based on a small number of patients. The high rate ratio of 34 we found for stroke patients with a pulmonary infection is not necessarily an overestimate, but emphasizes the lethality of pulmonary infection in these patients. Stroke patients often have swallowing problems and diminished cough reflexes, and thus are more prone to develop an aspiration pneumonia which is clinically more serious than an ordinary pneumonia or upper respiratory tract infection. Maybe it was decided not to give them antibiotic treatment anymore. Unfortunately it was impossible to recover which type of pneumonia was the cause of death in the involved patients.

Inability to walk is a well-known sign that a patient has become more demented. "Not being occupied in useful activity" might indicate other symptoms of severe dementia (increased apathy, apraxia, decreased interest in the outer world). "Restless at night" indicates sleep-wake disturbances. The relation between the item "uttering physical complaints" and severe dementia is not directly obvious: the item can indicate that one feels sick, or that one tries to communicate with others. Other observa-

tions about the prognostic value of *behavioural items* were reported for the elderly in general[24-26], and in institutions [27]. Remarkably the cognitive impairment measured on the behavioural rating scale was not related with survival anymore after adjusting for comorbidity. Probably "physical functions" have more impact on survival than "cognitive functions" [6], but it is also possible that the scale used was not powerful enough to discriminate between patients with mildly and severely cognitive impairment, because the scale consists of only 4 items.

The rate ratios of *gender and age* were somewhat lower than they would be without adjustment for the other variables (1.9 and 1.05 respectively), but they retained a considerable, statistically significant predictive value. This implies that the difference in survival chances between men and women are at most only partially explained by the somewhat higher severity of dementia at admission for men. The same is true for age and comorbidity: a positive correlation between comorbidity and age (adjusted for severity of dementia) can only partially explain a higher mortality with age.

Early studies had suggested that patients with a multi-infarct dementia had a better prognosis than patients with a Senile Dementia of the Alzheimer's type [5,28,29], and in several recent studies SDAT - patients had a better prognosis [6,30-35]. In our study there was no difference in prognosis after adjustment for other variables.

Model evaluation

The goodness-of-fit of the model was adequate, and the model can thus be used as a help in predicting survival in nursing home patients. The prognostic chart is easy to use, and the predicted survival chance is shown in Figure 3.

Nevertheless, many patients had an intermediate survival chance, and, although the predictive power of the overall model was higher than that of the other 3 models, it did not exceed 50%. Probably there is a limit in what can be expected from a predictive model that contains only information about patient characteristics at admission. For instance, if a patient with a prognostic index of 40 gets a pulmonary infection 8 weeks after admission, complicated by a heart failure, his prognostic index increases to 60 and his predicted two-year survival chance decreases from about 50% to about 15%.

Comorbid illness and chronic impairment complicating dementia can lead to difficult decisions for the nursing home physician, e.g. whether the patient should be operated, or be sent to hospital[36]. Decision problems also arise in elective surgery such as a lens-implantation in case of a senile cataract, in secondary prevention, such as a diagnostic evaluation in case of a suspected malignancy, or in the choice of type of surgery (a total or a partial hip replacement).

Often the demented patient is not able to grasp the implications of the decision-option and usually he has made no statements about his wishes earlier. In such a situation the nursing home physician wants to make the decision together with close relatives and the multidisciplinary team which takes care of the patient. The medical condition of the patient and the expected benefit of the treatment-option are of great importance [37]. Especially if treatment causes much burden and inconvenience initially, and the patient may only benefit from it later, knowledge about the patient's prognosis is important: the higher his life-expectancy, the higher the expected benefit in the future and the more reason there is for an active approach [38]. The presented model contains much prognostic information and thus can be of help for the clinician in estimating prognosis. The clinician himself however remains responsible for an adequate assessment of the validity of the model-based prognosis in the individual patient, because the patient can show specific signs and symptoms which are not accounted for in the model. Furthermore the clinician has to consider other important aspects such as quality-of-life and community norms in his decision options.

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Appendix

Prognostic scoring chart filled out for two patients with dementia.

		Patient A	Patient B
gender	if man	6	6
age	age < 55	0	0
	age 55 - 64	3	3
	age 65 - 74	6	6
	age 75 - 84	9	9
	age ≥ 85	12	12
pulmonary infection and stroke	if present	35	35
pulm. inf. without stroke	if present	4	4
atrial fibrillation	if present	8	8
parkinsonism	if present	5	5
heart failure	if present	6	6
malignancy	if present	8	8
diabetes mellitus	if present	5	5
needs help when walking	some	3	3
(no - some - much)	much	6	6
occupied in useful activity	sometimes	3	3
(often - sometimes - never)	never	5	5
restless at night	sometimes	2	2
(often - sometimes - never)	often	5	5
utters physical complaints	sometimes	2	2
(often - sometimes - never)	often	4	4
Add relevant scores:	Prognostic index:	52	24

Patient A was an 87-year old man with atrial fibrillation, heart failure, and diabetes mellitus, who needed much help when walking, was never occupied in useful activity, and often uttered physical complaints. His prognostic index was 52. Figure 3, which gives the predicted survival chances for every time after admission for several values of the prognostic index, shows that his chance of surviving 1 year is about 10%, and the chance of surviving two year is $0.55^{e^{(52-22)/10}} = 0.55^{e^3} = 0\%$. Patient B was a 85-year old woman, who had also a pulmonary infection, but no stroke, atrial fibrillation, and no incapacities on the 4 behavioural items. Her index was 24, and her predicted two-year survival chance was $0.55^{e^{(24-22)/10}} = 0.55^{e^{(0.2)}} = 0.55^{1.2} = 0.48$.

Chapter 6. The course of dependency in patients with dementia in a skilled nursing facility

Dementia is a progressively invalidating syndrome with a high prevalence in the elderly. Sooner or later demented patients become dependent on others, and require continuous supervision and care. The dependency is mainly the result of dementia-related symptoms such as memory disturbances, apraxia and incontinence. In general, the more severe the dementia, the more symptomatology exists, and the higher the dependency. Several behavioural rating scales have been developed to describe severity of dementia, or symptomatology [1-6]. In many studies these scales have been used to give a cross-sectional description of the population under study. Longitudinal studies, which describe the course of dementia over time often have a short duration of follow-up [7,8] or concern a small cohort [9-11]. Knowledge about symptomatology and progression is important from a scientific point of view (natural history, subtypes), for planning, for patient care, for informing the family, and for evaluation of therapeutic activities [12]. In this follow-up study, which is part of the "Rotterdam skilled nursing facility dementia project" [13], we will investigate the time course of dependency in activities of daily living after admission to a skilled nursing facility and explore whether there are differences in increase in dependency between several patient groups.

Methods

Patients

The study population consists of 397 patients with dementia (mean age 81.2 years, SD 6.6 years), consecutively admitted between 1984 and 1989 to Stadzicht, a psychogeriatric skilled nursing facility with a capacity of 261 beds. Before admission every patient underwent a multidisciplinary examination by a nursing home physician, a psychologist and a social psychiatric nurse. Only patients with a diagnosis of dementia were admitted. There are eight nursing wards and one observation ward. Each ward has 25 to 30 patients, and between the wards there is no difference with respect to mildly, moderately, and severely demented patients. Men (N=105) had a mean age of 80.3 years (SD 7.2 years), women (N=292) 81.5 years (SD 6.4 years). 340 Patients had Senile Dementia of the Alzheimer's Type (264 women and 76 men), and 56 patients had multi-infarct dementia (27 women and 29 men).

Criteria for dementia

A clinical diagnosis of dementia was made before and at admission by a multidisciplinary team on the base of amnesia, cognitive deficits and personality changes, according to criteria of the DSM - III - R [14]. The diagnosis of possible Senile Dementia of the Alzheimer's type (SDAT) was made according to McKhann [15]. A clinical distinction between SDAT and multi-infarct dementia (MID) was based on mode of onset, clinical course, a patchy loss of functioning, neurological symptoms and signs [16]. High resolution CT-scanning was not available.

Methods

Dependency was measured on the Dependency subscale of the *BOP* (Beoordelingsschaal voor Oudere Patiënten), a 35-item behavioural rating scale for the elderly in the Netherlands [2,3,17]. This scale is, like the Clifton Assessment Procedures for the Elderly [4] derived from the Stockton Geriatric Rating Scale [1]. The subscales are based on a factor analysis, performed on 965 institutionalized elderly, of whom about 50% were demented [2]. The items are behaviourally anchored. The Dependency scale consists of 23 items. Nurses who take care of the patient score each item on a 0 - 1 - 2 scale, with a higher score indicating more severe or frequent disability, or more help needed. Sumscores can thus take values between 0 and 46. The interrater reliability of the Dependency scale in the original analyses was high (Spearman correlation coefficient 0.91 [2]. The scale is used to differentiate patients in degree of dependency in many Dutch Nursing Homes [17,18]. Patients with a score below 17 are called 'mildly' dependent, patients with a score between 17 and 29 points "moderately" dependent, and those with a score of 29 or higher "severely" dependent [19]. These cut off values very much resemble the values of 16 and 31 that were used in a study in which the time required for patient care was related with the score on the Dependency scale [17].

During follow-up the Dependency scale was filled out within a month after admission (referred to as score at admission), and subsequently with time intervals between 2 and 6 months. With these data for every patient Dependency scores at 2-month intervals were calculated. In order to estimate these scores we assumed a linear increase (or decrease) over time between two scores on the Dependency scale. For instance, if a patient scored 9 points on the Dependency scale 90 days after admission, and 21 points 210 days after admission, his linearly interpolated score would be 12 at day 120, and 18 at day 180. If a patient had died, we used the last score until the time of death. We also tried some other interpolation methods, but results and conclusions were not influenced. With these scores the patients were assigned every 2 months to the categories mild, moderate or severe dependency, or

death. The changes over time since admission in the relative frequency of the categories were calculated (see Figures 1 and 2). Finally, transition probabilities between these categories within half-year periods were computed using a Markov model. These probabilities are the averaged chances (weighted for number of patients) for the subsequent time intervals (0.5 - 1 year, 1 - 1.5 year, etcetera).

Patient-flow during follow-up

Dependency scale measurements were not available for 7 of the 397 patients. Furthermore 22 patients died and 11 patients were lost to follow-up within a month (Table 1). During the entire 3 years 33 patients with available Dependency scale measurements were lost to follow-up: 8 patients went home, 23 patients went to another skilled nursing facility, and from 2 patients the destiny was unknown. The mean age at admission of these 33 patients (12 men and 21 women) was 79.4 years (SD 7.1). This was lower than for the other patients (81.3 years, SD 6.6), but this difference was not statistically significant.

Table 1. Number of patients during subsequent periods after admission.

period	BOP available	death	lost to follow-up	alive at end of follow-up (1-1-90)	total
0 - 1 month	364 *	22	11	0	397
1 month - 1 year	244	95	18	0	357
1 year - 2 year	160	44	3	37	244
2 year - 3 year	86	41	1	32	160

* in 7 patients BOP - scores were missing

All patients who were not lost to follow-up or did not die within a year had at least one year of follow-up. Patients admitted in 1988 had at most 2 year of follow-up; 37 of them were still alive at January 1st, 1990, and thus withdrawn alive (see Table 1). Patients admitted in 1987 could have at most 3 years of follow-up: 32 of them were still alive at January 1st, 1990 and thus withdrawn alive. In total, 180 patients died, 22 were lost to follow up and 69 patients were still alive at January 1st, 1990.

Results

The 357 patients with a BOP available at admission had a mean score on the Dependency scale of 19.6, corresponding with a mean item score of 0.85, and a standard deviation of 8.7. See the Appendix for the mean scores on each of the items of the Dependency scale at admission. On average, the mean score increased from 19.6 at admission to 21.3 after one year and 27.0 after three years. Men had significantly higher scores than women (Table 2). Patients coming from their own house were less dependent, and patients coming from the homes for the aged were more dependent than the other patients.

Table 2. Mean scores for dementia patients on the Dependency subscale of the BOP geriatric rating scale, shortly after their admission to a nursing home. Scores can range between 0 and 46, indicating no resp. much impairment on all of the 23 items of the subscale.

	Number of patients (%)	Mean score (SD) on the Dependency subscale		
Total	357 *(100%)*	19.6	(8.7)	
Gender				
Men	84 *(24%)*	21.2	(8.1)	a
Women	273 *(76%)*	19.1	(8.8)	
Age				
< 80	148 *(41%)*	19.3	(8.9)	ns
≥ 80	209 *(59%)*	19.8	(8.5)	
Place of living				
Home	148 *(41%)*	17.7	(8.6)	b
Home for the aged	61 *(17%)*	22.9	(6.8)	b
Nursing home	60 *(17%)*	20.0	(9.0)	ns
Hospital	78 *(22%)*	20.4	(9.0)	ns
Others	10 *(3%)*	17.7	(8.5)	ns
Type of dementia				
MID	44 *(12%)*	21.2	(7.7)	ns
SDAT	312 *(88%)*	19.4	(8.8)	

a t-test, $p < .05$

b t-test, $p < .001$ (compared with mean of the 4 other groups together)

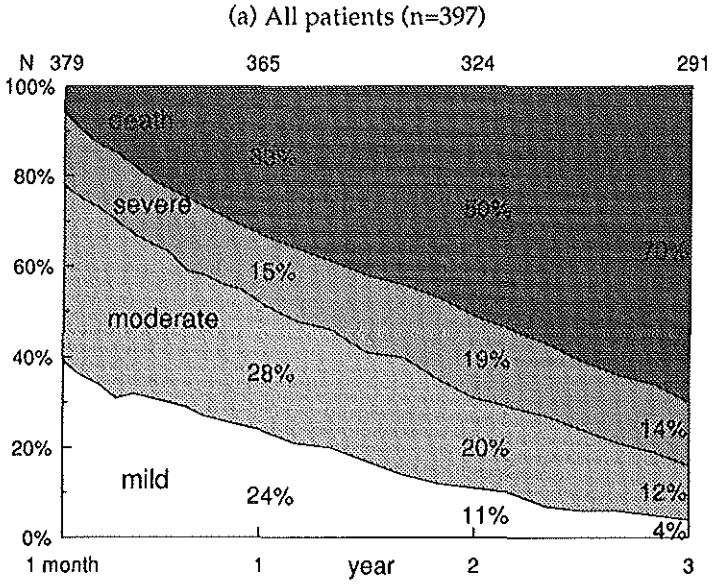
ns t-test, non-significant on a .05 level

Relative frequency of Dependency categories over time

Figure 1a shows the relative frequencies of the dependency categories over time since admission. At entry 41% are mildly, 42% moderately and 17% severely dependent. The proportion of mildly dependent patients decreases to 4% after 3 years, while 70% of the patients have died, 12% are moderately dependent, and 14% are severely dependent.

For the patients still alive there is a shift towards more dependency (Figure 1b). After one year, 35% of the patients is mildly dependent, and after 3 years only 14%. The proportion of moderately dependent patients remains constant (42% and 41% after 1 and 3 years respectively). The proportion of severely dependent patients doubles from 23% after 1 year to 45% after 3 years.

Figure 1. Distribution of Dependency categories over time in dementia patients during their stay in a nursing home.



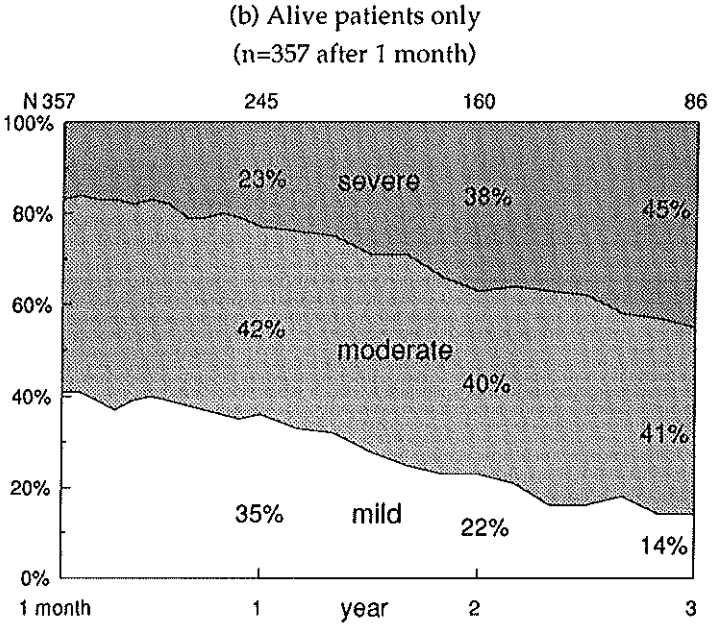
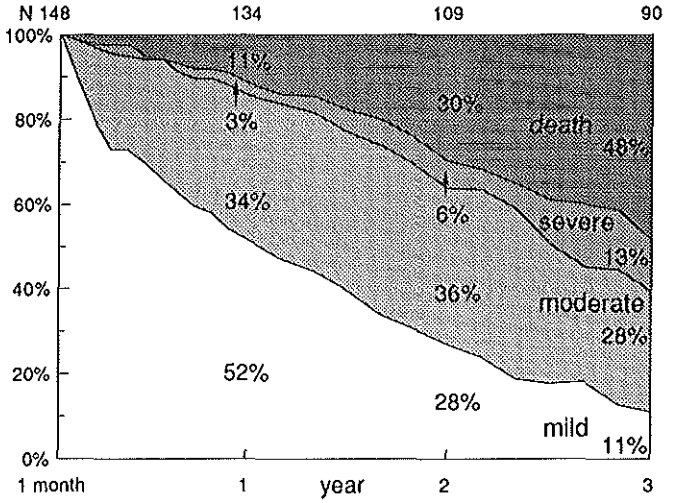


Figure 2 stratifies for Dependency category at admission. Patients with mild dependency gradually deteriorated over time (Figure 2a). After one year only 52% and after three year only 11% still was mildly dependent. A small proportion of patients moderately dependent at admission temporarily improved to mild dependency (Figure 2b). After 3 year most of the moderately dependent patients (77%) have died. Remarkably their three-year survival did not differ from patients who were severely dependent at admission (Figure 2c). This may well be a chance finding (only 60 patients were severely dependent at admission). About 20% of the severely dependent patients improved in the period shortly after admission. For the other patients the severe dependency was irreversible.

The relative frequency of the Dependency categories over time did not essentially differ between male and female patients, between patients under 80 and over 80, and between SDAT-patients and MID-patients, with the exception of the sex-specific death rates which were higher for male patients than for female patients.

Figure 2. Change in Dependency category over time for patients with dementia during their stay in a nursing home. All percentages are relative frequencies. For instance, 1 year after admission 11% of the 134 patients mildly dependent at admission have died, 3% are severely dependent, 34% are moderately dependent, and 52% are still mildly dependent. The other 14 patients did not have 1 year of follow up because they had left the nursing home.

(a) Mild dependency (n=148)



(b) Moderate dependency (n=149)

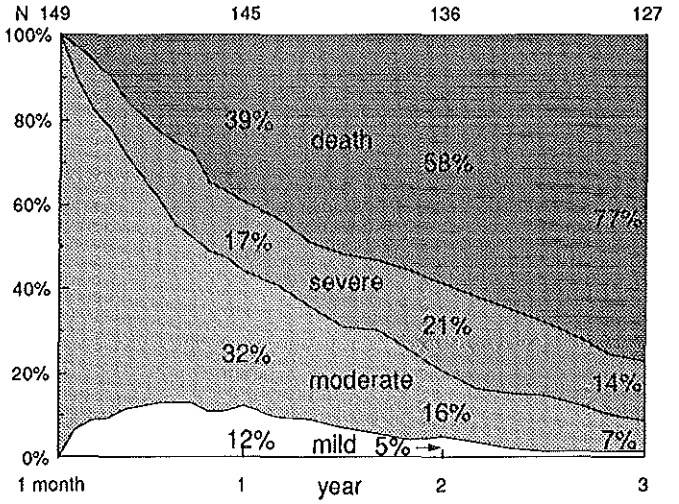
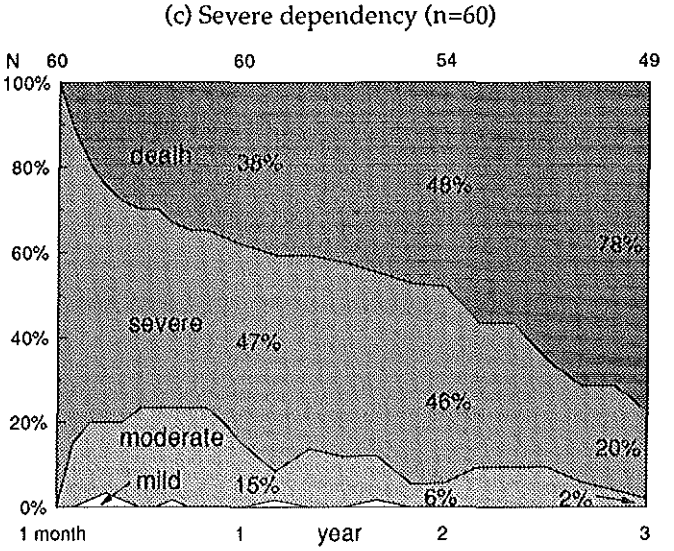


Figure 2 (continued)



Transitions between dependency categories

The probabilities for transitions between dependency categories during half year time periods are shown in Figure 3 and Table 3. Differences between half-year intervals could be explained by chance fluctuations. About 2/3 of the patients remained in the same category. About 1/4 of the patients was one category worse half a year later if we consider death as 1 category worse than severe dependency. Only 5% of the patients improved. Transition from mild to severe dependency within 6 months periods occurred only in 1% of the cases. The chance of dying increased with dependency. Both the chances of improving and the chances of dying of the first half year exceeded those for the later periods (see Table 3).

Figure 3. Half-yearly transition probabilities in Dependency category for 357 patients with dementia between a half and three years after admission. Cycle length is 0.5 year.

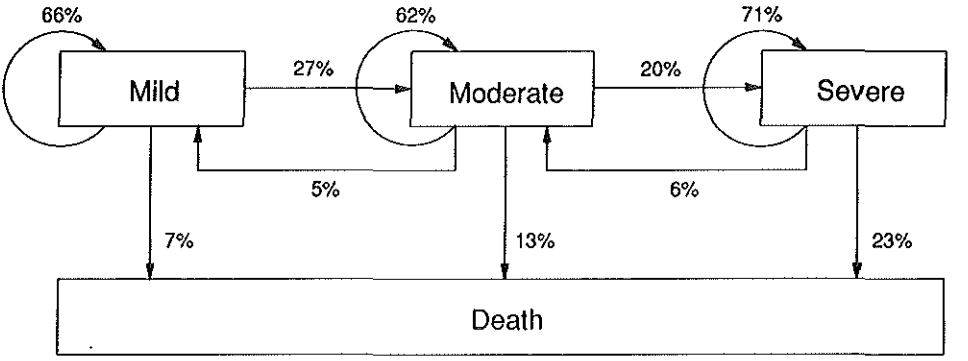


Table 3. Changes in grade in Dependency for 357 patients with dementia during the first 3 years after admission.

Grade of Dependency	Grade of Dependency half a year later	Transitions during the first half year	Mean transition per half year, between 0.5 and 3 year	Extreme values of the 5 transitions between 0.5 and 3 year
from Mild	to Mild	70%	66%	57% - 71%
	to Moderate	24%	26%	23% - 33%
	to Severe	1%	1%	0% - 2%
	to Death	5%	7%	5% - 15%
from Moderate	to Mild	12%	5%	3% - 7%
	to Moderate	54%	62%	54% - 67%
	to Severe	14%	20%	16% - 30%
	to Death	19%	13%	8% - 16%
from Severe	to Mild	0%	0%	0% - 0%
	to Moderate	23%	6%	2% - 13%
	to Severe	47%	71%	62% - 81%
	to Death	30%	23%	12% - 34%

Prognostically distinct subgroups

In order to identify patients categories with a more rapid or with a more slowly rate of progression, the course of dependency of the 109 patients who were mildly at admission and had at least 2 years of follow-up, or died within this period was studied in more detail (Table 4). There was no category of patients, in which the mortality or the distribution between dependency categories substantially differed from other categories, except maybe the patients with a duration of the dementia before admission between 3 and 6 years, in whom only 17% died, as compared to the more than 30% mortality for shorter or longer duration.

Table 4. Mildly dependent patients at admission, their characteristics, and their situation 2 years later.

		Situation 2 years after admission		
	Number of patients (%)	Mildly dependent	Moderately /severely dependent	Dead
Total	109 *(100%)*	28%	42%	30%
Gender				
Men	20 *(18%)*	20%	40%	40%
Women	89 *(82%)*	29%	43%	28%
Age				
< 80	49 *(45%)*	29%	45%	27%
> 80	60 *(55%)*	27%	40%	33%
Place of living				
Home	55 *(50%)*	22%	45%	33%
Home for the aged	6 *(6%)*	50%	33%	17%
Nursing home	22 *(20%)*	23%	55%	22%
Hospital	23 *(21%)*	35%	26%	39%
Others	3 *(3%)*	67%	33%	0%
Duration (N=103)				
≤ 3 year	33 *(32%)*	18%	42%	39%
3-6 year	35 *(34%)*	43%	40%	17%
≥ 6 year	35 *(34%)*	20%	49%	31%
Type of dementia (N=108)				
MID	13 *(12%)*	8%	69%	23%
SDAT	95 *(88%)*	29%	39%	32%

Discussion

This study confirms that patients with dementia become more dependent over time. Nevertheless, several patients in our cohort were still mildly dependent after a 3-years period. Improvement occurred seldom, except during the first half year after admission, possibly because of patients becoming more familiar with their new environment. After six months improvement was rare and temporary. These observations are in accordance with earlier observations in a Dutch skilled nursing facility [20]. The few studies which give quantitative information about rate of increase in severity of dementia, concern results on cognitive tests such as the Blessed Information Memory Concentration Test [10, 21, 22], and the Mini Mental Status Examination [3, 21 - 23]. Most of them are not based on institutionalized patients. Longitudinal studies by means of behavioural rating scales are reported for the Clinical Dementia Rating Scale [9], the Blessed Dementia Rating Scale [9, 22], and the Alzheimer's Disease Assessment Scale [8, 11]. Interpretation of changes and comparison between different scales are very difficult.

We described the time course in dependency in activities of daily living in dementia patients in a skilled nursing facility as measured on a subscale of a behavioural rating scale. Several items, such as "makes repetitive vocal sounds", and "engages in useless repetitive activity" do not seem to express dependency directly, but were nevertheless included in the subscale after a factor analysis [2]. The face validity of this subscale is supported by the strong association between the score on this subscale and the amount of help needed in a skilled nursing facility: the "mild", "moderately" and "severely" dependent patients needed for basic care (washing, dressing, feeding, nursery-specific activities like wound care), about 60, 130 and 150 minutes per day respectively [17]. The total daily help for these three groups was 140 (SD 20), 230 (SD 63) and 230 (SD 43) minutes per patient respectively. There were less minutes per day spent on "non-basic patient care" (social activities, drinking coffee or tea) for "severely" dependent patients (25 minutes) than for "moderately" or "mildly" dependent patients (55 and 45 minutes respectively), probably because of their impaired communicative abilities [17]. The Stadzicht population consists of about 25% "mildly" dependent patients and 75% "moderately" or "severely" dependent patients (see Figure 1, lower part): thus the average resident in Stadzicht needs about 205 minutes (0.25 * 140 minutes + 0.75 * 230 minutes).

Research on the course of dementia or on subtypes of dementia (of the Alzheimer's type) is difficult and hazardous. Many symptoms and signs occurring in the time course of dementia can also be caused (or influenced) by medical conditions such as stroke, fractures, Parkinson's disease, visual impairment, and hearing impairment.

Scores on cognitive scales also depend on premorbid intellectual level; behavioural disturbances (apathy, aggression) are often related with premorbid personality. If differences between scores on a rating scale are used (e.g. the annual rate of change), ceiling effects can give an underestimate of change. The meaning of transition probabilities as e.g. used in our study, can also be overestimated if patients have scores near the cut off values: a change in score from 16 to 17 on the Dependency scale, which is clinically irrelevant, means that the patient changes from "mildly" to "moderately dependent". Berg et al. recommend the use of a growth-curve model [25]. This model, described by Laird and Ware [26], can cope with different numbers of observations between patients.

Sometimes dementia subtypes are derived from minimal evidence: Mayeux and colleagues found 4 subgroups of dementia of the Alzheimer's type: an "extrapyramidal", a "myoclonic", a "benign" and a "typical" subgroup [27]. Their finding was based on a very small number of patients, and the subgroups differed in severity at entry into the study. Until prospectively validated in other studies, the hypothesis of 4 subgroups should better be regarded as suggested than as tested. A more powerful analysis of subgroups should be based on a larger number of patients and requires adjustment for severity at entry into the study [28]: subtypes should be defined by their total course of deterioration [29]. In a large cohort study Corey-Bloom found no significant differences in rates of change on the MMSE in patients with or without extrapyramidal signs [22]. In our study, data about extrapyramidal signs and myoclonus were not systematically recorded. Therefore we were not able to investigate whether the 4 subgroups, proposed by Mayeux, showed differences in Dependency over time. We found no differences in the course of dependency for several other major subgroups (age, gender, type of dementia). The subgroups did not essentially differ in dependency at admission, and they showed no significant differences over time, except the already mentioned sex-difference in mortality. It was thus not possible to predict which patients who were mildly dependent at admission remained stable, and which patients became severely dependent in a 2-years period. Interestingly, the mean Dependency score at admission of the mildly patients who remained stable was significantly lower (8.8, SD 3.8) than the score for those who were moderately (mean score 11.3, SD 3.5), or severely (14.7, SD 1.0) dependent after 2 years: the latter were already slightly more demented at admission, but nevertheless the difference in mean Dependency score with the first group must have increased considerably during the two years after admission.

In conclusion, this longitudinal analysis gives a quantitative, behaviourally anchored summary of the gradual increase in dependency in dementia patients. Improvement was uncommon and temporary. Interestingly, sudden deterioration from mild to severe dependency also occurred very infrequently. Such information can be very informative for planning and management, and for the nursing staff and the family of the patient. Further research is required for the classification of Alzheimer's disease into prognostically distinct subtypes.

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Appendix

Description of Dependency

The Table gives the mean scores on the items of the Dependency-scale at admission for mildly, moderately and severely dependent patients. The sumscore is useful for an overall impression of severity, but gives little information on individual items. For instance, for the mildly dependent patients, the mean itemscore on "needs assistance when eating" is 0.31. Patients with a score of 0 do not need any help when eating, and those with a score of 2 need much help. So, on average, the mildly dependent patients do hardly need any help when eating, and the severely dependent patients mostly need much help when eating (mean itemscore 1.60). Other items show already much impairment for the mildly dependent patient ("does not know in which institution he is", "helps out on the ward") or show relatively little impairment even for the severely dependent ("urinates and defecates at the wrong place", "does not respond to his name").

Table A. Mean scores on the 23 items of the Dependency scale at admission. Items have scores of 0, 1 and 2, indicating increasing problems with the item concerned. A score at admission between 0 and 16 on the 23 items means "mildly" dependent, a score between 17 and 28 "moderately" dependent, and a score between 29 and 46 "severely" dependent.

		Mild (N=148)	Moderate (N=149)	Severe (N=60)	Overall (N=357)
1	needs assistance when eating	0.31	0.96	1.60	0.80
2	incontinent during the day	0.28	0.99	1.63	0.80
3	does not make himself understood	0.23	0.73	1.37	0.63
4	unable to find his way around the ward	1.30	1.86	1.95	1.64
5	does not know in which institution he is	1.34	1.75	1.92	1.61
6	does not know any of personnel by name	1.80	1.95	1.97	1.89
7	does not understand others	0.36	0.63	1.13	0.60
8	does not respond to his name	0.01	0.12	0.68	0.17
9	occupied in useful activity	0.71	1.27	1.75	1.12
10	socializes with other patients	0.61	1.23	1.78	1.07
11	urinates and defecates at the wrong place	0.14	0.44	0.50	0.33
12	helps other patients without being asked	0.95	1.67	1.98	1.42
13	unwilling to do things asked of him	0.46	0.70	1.02	0.65
14	engages in useless repetitive activity	0.59	0.80	1.38	0.81
15	makes repetitive vocal sounds	0.22	0.49	0.93	0.45
16	never starts conversations	0.53	1.14	1.63	0.97
17	privileges to leave the ward	1.00	1.01	1.00	1.00
18	drowsy during daytime	0.18	0.68	1.27	0.57
19	needs assistance when dressing	0.68	1.49	1.93	1.23
20	incontinent at night	0.28	1.14	1.65	0.87
21	needs protection from falling out of bed	0.13	0.69	1.52	0.60
22	objectionable during the night	0.23	0.29	0.32	0.27
23	restless at night	0.18	0.31	0.27	0.25

Chapter 7. Falls in dementia patients.

Falls are one of the major causes of disability and mortality in the elderly and therefore represent an important health problem [1,2]. Most incidents do not have serious consequences, but they may cause fractures or other serious injuries. Several reviews have already summarized the number and type of falls in the elderly [1,3,4].
Studies varied widely in patient population (volunteers, healthy elderly, patients with dementia) and in institutional setting (people living at home, hospitalized patients, nursing home patients). Sometimes the number of falls per person-years was recorded [5], and sometimes the percentage of fallers and non-fallers in a certain time-period [6] or the percentage of recurrent fallers [7,8]. Besides that there was much variation in criteria as to what constitutes a fall [4]. Therefore a valid comparison between the many reported fall-rates in the literature is very difficult.
The relative importance of these patient-related risk factors increases with age [1,3]. Probably this is caused by the higher prevalence in the elderly of conditions such as orthostatic hypotension, M. Parkinson, impaired mobility, muscle weakness, balance and gait disturbances, arthritis, visual problems, a history of previous falls, general decline, toxic reactions to drugs and the increasing number of drugs prescribed [2,8-11].
Only few studies about falls have been carried out in patients with dementia. Morris found that the presence of dementia itself was a major risk factor for falling [12]. Many of the medical conditions just mentioned were also associated with an increased fall risk in patients with dementia [6]. Brody reported that high levels of physical vigour and significant decline in vigour were associated with falls [13]. We are not aware of other studies, which have assessed the association between the risk of falling and the severity of dementia, or changes in the risk of falling at different times after admission.
This study reports an analysis of reported falls during a 2-year period in a nursing home for demented patients. We will evaluate whether risk factors for falling in the elderly such as female gender, higher age, physical and cognitive impairment are also associated with higher fall rates in dementia patients. Additionally it will be analyzed whether the risk of falling is higher just after admission or after transferral from one ward to another. In combination with attention to other patient-characteristics and environmental hazards these results may contribute to prevention of falls and their consequences.

Material and methods

Patients

Stadzicht is a psychogeriatric nursing home facility with 261 beds, specially designed for the continuous care of patients with dementia and more or less similar to British nursing homes [14]. After admission a patient first remains for at least 6 weeks on a special observation nursing ward, where he or she is evaluated medically and psychologically. After this period the patient goes to one of the 8 other nursing wards. Because these wards all house both mildly and severely demented patients, patients are not transferred to another ward when they become more severely demented.

This study is a part of a research program about course of illness and survival in patients with dementia [15]. This analysis of falls concerns the 240 patients admitted since 1984 - when we started with the follow up registration of the geriatric rating scale - and were still alive at January 1, 1988. For the number of falls per person after admission, only the 71 patients admitted in 1988, when the registration of incidents had started, were evaluated.

Incidents

Since October 1987, Stadzicht uses a registration form on which incidents are recorded. The forms, filled out by the personnel immediately after an incident takes place, include information about type, date, place, and time of incident, possible causes, consequences, information about preventive measures, and the name of the patient. A special committee collects and analyses the forms, and reports the results to the personnel and the management of the nursing home. Our analyses concern the incidents reported in 1988 and 1989: observed falls and found on ground-incidents. An incident is coded as an observed fall if someone saw or heard a patient at the moment of falling. If a patient has been found sitting or laying on the ground, an incident is coded as a found-on-ground incident. Because these incidents are usually caused by falls, the two types are combined in the analyses referred to as falls.

Geriatric Rating Scale

The BOP is a geriatric behavioural rating scale for elderly people [16]. It is derived from the Stockton Geriatric Rating Scale [17]. It is filled out by the personnel about 3 times a year for every patient. Impairment is measured on 35 behavioural items, with no impairment scored as 0, 1 an intermediate score, and 2 corresponding with the most

severe impairment. Sum scores are derived on 6 subscales: dependency, aggressive behaviour, physical disability, depression, orientation & communication and apathy. The dependency scale consists of 23 items and gives an overall impression of the physical and psychological impairment, as well as a measure of severity of dementia [18]. Some examples of items on these scale are: "needs assistance when eating", "incontinent during the day", "needs protection from falling out of bed", and "unable to find his/her way around the ward". The physical disability scale consists of 3 items: "needs assistance when walking" , "needs protection from falling out of chair" and "needs assistance when dressing". The interrater reliability of the dependency and the physical disability scales in the original analyses was very high. The Spearman - correlation coefficients were 0.91 and 0.92 respectively [16]. For the other 4 scales the coefficients varied between 0.60 (depression) and 0.84 (apathy).

Statistical analysis

The fall-rates are expressed as falls per person year of observation. We linked the identity number of the patient with an incident to the clinical database for the study of prognosis in dementia patients. To explore the relationship between the risk of falling and the rating scale, we used the most recent score before the fall occurred. To examine the number of falls per person at different times after admission, we could considered only 71 patients admitted since 1988 when the incident registration was in place. We used the product-limit method for estimating survival chances [19].

Results

Patient characteristics

The population under study consisted of 240 patients, 46 men and 194 women. Of these, 169 patients resided in the nursing home at January 1, 1988. Their mean length of stay as of this day was 1.5 years. The other 71 patients were admitted in 1988. During the observation 103 patients died, 8 patients were discharged alive, and 129 patients were still alive and residing in the nursing home on January 1, 1990. The mean age at entry into this study was 81.4 year (SD 6.7): 80.4 (SD 7.0) for men and 81.7 (SD 6.5) for women. No scores on the rating scale were available for 19 patients (8%). Mean scores at the dependency subscale at entrance into this study was 21.3 (SD 9.1), 21.4 (SD 7.9) for men, and 21.3 (9.4) for women; 74 patients (34%) were con-

sidered mildly demented (less than 17 points on the dependency subscale), 91 patients (41%) moderately demented (a score between 17 and 28 points), and 56 patients (25%) severely demented (a score above 28 points). Men were somewhat more demented (relative proportions 34%, 32% and 34% versus 33%, 40% and 27% for women). The characteristics of the 71 patients admitted during 1988 (12 men and 59 women) did not essentially differ from the 169 patients admitted earlier.

Falls

During the 2-year observation period, 735 observed falls and 608 found-on-ground incidents were reported for the 240 patients (Table 1). As the ratio between the number of these two types of incidents (735/608 = 1.2) did not depend on any patient-characteristic or time after admission, we aggregated the results on both types of falls. Thus the 240 people had 1343 falls with 329 person years of observation. This is equivalent with 4.1 falls per patient per year.

Table 1. Falls per personyear and number of falls by type of fall and gender in 240 dementia patients admitted to a nursing home.

	Falls per personyear (number of falls)			rate ratio
	Total	Men	Women	men/women
Type of fall				
observed	2.2 (735)	3.6 (187)	2.0 (548)	1.8 (1.6 - 2.1) *
found-on-ground	1.9 (608)	3.3 (169)	1.6 (439)	2.1 (1.8 - 2.5)
Age group				
< 75	4.0	5.1	3.7	1.4
75 - 79	4.1	8.9	3.3	2.7
80 - 84	4.7	8.4	4.1	2.1
85 -	3.4	5.5	3.0	1.8
Total	4.1	6.9	3.6	1.9
All falls	4.1 (1343)	6.9 (356)	3.6 (987)	1.9 (1.8 - 2.1)

* 95% confidence interval

Gender and age

The risk of having a fall for men was almost twice the risk for women (6.9 versus 3.6 falls per py) . There was no trend towards an increased risk of falling with age: differences between the 4 age-groups were small and inconsistent (Table 1). For each age-group male patients had higher fall rates than women: the rate ratio varied between 1.4 and 2.7 for the 4 age-groups.

Time after admission

The risk of falling was especially high in the first week after admission (Table 2). The 71 patients whose falls where reported during their first week after admission had 18 falls. Together they had 495 person days of observation. This implies 18 * 365 / 495 = 13.2 falls per personyear. Later on, the risk of falling declined. For instance, the 110 patients whose falls were assessed in their second half year after admission, had 173 falls in 46 person years of observation, corresponding with only 3.8 falls per person year. The temporary increase in the risk of falling after 6 weeks can probably be explained by the transfer to another ward (Table 2). The first week after this transfer was accompanied with a higher risk of falling (9.5 falls per py). Again, this risk declined later, with a temporary, modest increase in the second year.
With the exception of the first two weeks after admission, fall rates were considerably higher for men: in the first and second week after admission the fall risks per person year were 13.0 and 4.4 for men, and 13.3 and 5.5 for women. At any time after admission from the observation ward the fall risk for men was also higher, except during the fifth year.
Of the 71 patients admitted since 1988 and alive at follow up periods, only a third of the patients had no fall in the first two months, and a quarter already had 2 or more falls. At 1 year, only 15% still had no falls, and two-thirds already had 2 or more falls. These fractions did not change anymore after 18 months.

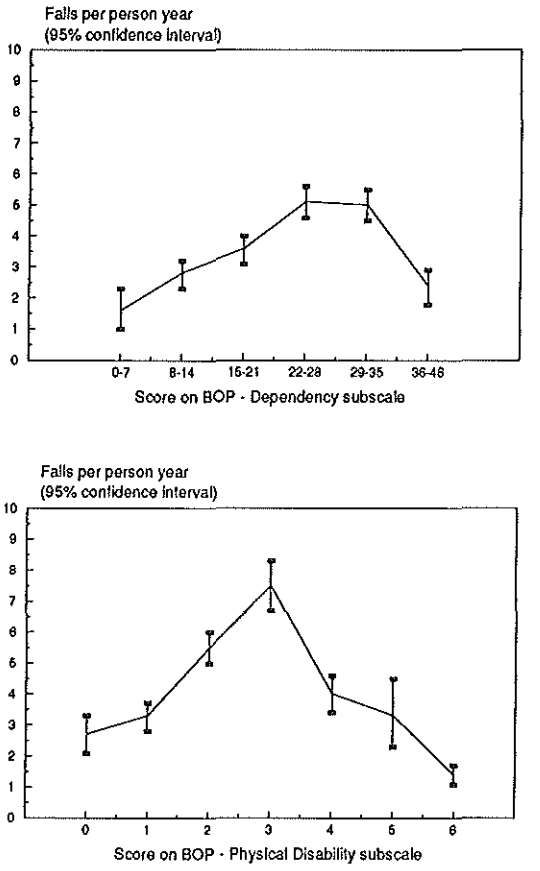
Table 2. Falls per person year and number of falls at different times after admission to the nursing home or after transfer from the observation ward.

	After admission to nursing home		After transfer from observation ward	
time period	N	falls per person year (number of falls)	N	falls per person year (number of falls)
week 1	71	13.2 (18)	99	9.5 (18)
week 2	70	5.3 (7)	98	5.4 (10)
weeks 3-6	74	4.4 (23)	99	4.8 (35)
weeks 7-13	83	7.0 (71)	103	4.1 (51)
weeks 14-26	99	5.7 (118)	107	3.4 (81)
year 0.5-1	110	3.8 (173)	121	3.7 (181)
year 2	148	4.1 (370)	145	4.7 (392)
years 3-4	140	3.8 (477)	114	3.6 (392)
year 5+	41	3.1 (83)	21	2.3 (27)

Geriatric Rating Scale

The risk of falling increased with the sum scores on the dependency scale up to a score of 28 and declined thereafter (Figure 1, upper part). The relative risk of falling in comparison with people scoring less than 8 on this scale varied from 1.5 to 3.1. The same pattern was found on the physical disability scale, in which people with a score of 3 had a 3 times higher risk than those with a score of zero (Figure 1, lower part). The same trend was present on the orientation & communication, and the inactivity scale (not shown). There was no relationship between the scores on the depression and aggressive behaviour scales and the number of falls. This pattern did not differ between men and women, and for each score men had higher fall risks than women.

Figure 1. Falls per personyear for several scores on the BOP - subscales Dependency and Physical Disability, for 221 patients with dementia admitted to a nursing home.



Causes, consequences, and preventive measures

Possible causes for the incidents mentioned on the registration form were "material, slipping (over urine), stumbling (17%), gait and equilibrium disturbances (16%), "sitting down incorrectly" (11%), "urge to walk in spite of physical inability to walk safely" (6%), "fatigue" (5%), "agitation, confusion, irritation" (4%), "(arguments with)

other patients" (4%) and "inattention of personnel" (2%). In 18% other causes were mentioned, and in 22% the cause was unknown. About 30% of the falls were rated as "preventable" on the registration form.
Most incidents were relatively harmless: they only upset the patient or resulted in minor pain and bruises. Nevertheless 206 patients experienced skin damage, and 17 of them had to be stitched. Twenty-two patients had a hip fracture (3 men and 19 women), 5 patients a wrist fracture, and 6 patients other fractures.
Possible causes for the hip fractures were "material, stumbling, slipping" (5 patients), "gait and equilibrium disturbances" (5 patients) , "(arguments with) other patients" (2 patients) and "inattention of personnel" (1 patient). In 4 cases other causes were mentioned, and 7 times the cause was unknown. Eight of the hip fractures were reported as "preventable". As could be expected, hip fractures were associated with increased mortality: the 3-months survival rate after a hip fracture was 76%, and the one-year survival was 53%, whereas in general 75% of patients survive each subsequent year of admission.

Discussion

This analysis of incidents in a nursing home for patients with dementia revealed a fall-rate of 4 falls per person per year. Only 1 out of 4 patients had no fall within the first year after admission. Although the majority of incidents did not result in serious damage, 22 hip fractures were reported.
More detailed comparisons require a clear definition of what is considered as an incident, and the development of a standard registration form, which has to be filled out for each incident [20-25]. Information about the incidents and the surrounding circumstances is needed for insight in environmental hazards and patient-related risk factors.
Some results deserve special attention. Knowledge about fall-rates is often based on studies in the non-institutionalized (healthy) elderly, and information about falls in these studies is often obtained by interviews rather than by incident report forms. The number of incidents in these studies varied between about 200 and 600 incidents per 1000 persons per year [4]. This number is much lower than the fall-rates in hospital-based surveys and long-term institutional surveys: the number of incidents in these institutions varied between 650 and 3600 per 1000 beds per year [4]. Two reasons for these higher rates can be mentioned. With the interview method in the non-institutionalized elderly, probably only the more serious falls tend to be recorded, whereas the use of incident report data might overestimate the importance

of fall incidents, because most falls had no serious consequences. Furthermore, hospitalized or institutionalized patients are usually less healthy than elderly living at home. They have more chronic disabilities, and thus a higher risk of falling. Our annual 3770 incidents per 1000 beds is just outside the range of fall-frequency in institutions. One explanation for this is that in our study all patients were demented, contrary to the studies just mentioned. A low mental status score (Set Test) and Senile Dementia of the Alzheimer's Type have been found to be associated with an increased risk of falling [8,12].

We found higher fall rates for men than for women. In many studies of healthy elderly people living at home [5], females are found to be more prone to falling. Around the house much accidents are associated with household activities, and most of these activities (such as cleaning windows) are usually performed by women. In institutions the relation between gender and fall rates seems less obvious: sometimes higher fall rates for men [26,27], and sometimes higher fall rates for women are reported [7]. In the only study of institutionalized demented patients that we are aware of, all patients were female [13], and that study found no relation between age and falls. This confirms our results: the dementia process and its associated cognitive and physical impairment have far more impact on the fall rates than age. The increase in fall rates over age, often reported in the literature, may even find a partial explanation in the increasing prevalence of dementia with age. We are not able to test this hypothesis, however, because none of the studies relates age-specific fall rates to the presence of dementia.

We used a Dutch rating scale for the evaluation of the impairment of daily functioning. The dependency subscale gives a general impression of the severity of dementia [28]. The other five subscales contain fewer items and focus on specific dysfunction. Five out of six subscales showed more or less the same pattern: the fall risk increased up to a certain score on a subscale, and declined thereafter. The fact that most falls occurred when a patient was walking (stumbling, slipping), that moderately demented patients often maintain their ability to walk but on average are less stable than the mildly demented patients, and that the severely demented patient on average becomes increasingly apathetic and has a decreased urge to walk, or becomes often wheelchair-bound or bedridden, might partially explain this finding.

There are some limitations to the generalizability of our findings. We used the last score recorded on the rating scale recorded prior to a fall, which may not accurately reflect the patients' dependency or physical disability at the moment of falling. Nevertheless, we thought it justifiable to use these scores because the population was fairly stable over time: about 60% of the patients, evaluated as mildly dependent

(a score between 0 - 16 on the Dependency scale), were still mildly dependent one evaluation later. The same was true for the moderately dependent patients. The severely dependent patients were even more stable: almost 90% was also severely dependent at the next evaluation. An increase in dependency may have occurred before a fall (and contributed to a fall), after a fall, or even because of a fall. A decrease in dependency occurred only occasionally.

Unfortunately we had no precise information about the fact whether the very dependent and physically impaired patients might be physically more restricted. On the other hand, the effectiveness of physical restraints in preventing falls is uncertain [29], or even counterproductive and risky [6]. Sometimes these measures can lead to functional decline, skin abrasions, or even accidental death by strangulation [29]. The occurrence of some accidents with physical restraints in Stadzicht has led to an investigation of their (wrong) use in order to develop a protocol, in which it is described when and how to use these measures.

When considering possibilities for prevention, it is useful to divide the risk factors for falling in intrinsic factors (patient characteristics) and extrinsic factors (environmental characteristics). Several reports [29,30] recommend how to rearrange the environment in order to eliminate the extrinsic risk factors as much as possible. The evaluation of intrinsic risk factors for falling in the elderly may lead to identification of the fall-prone patient [31,32]. The occurrence of a (serious) fall should always lead to a post-fall assessment. Rubenstein indicated that such an assessment could lead to a significant decrease in hospital admissions because of serious incidents [33].

We found that the first weeks after admission or after transfer to another ward were associated with a high fall risk. In this period many patients are confused by and unaccustomed to the new environment. Moreover, patients are often admitted because of a deterioration in the situation at home (or in a residential home), or after a stay in a hospital. Special efforts should be made to prevent these early falls: newly admitted and transferred patients should be paid special attention by the nursing staff, a pre-fall assessment should be made, and close relatives should be encouraged to stay with the demented patient as much as possible during this period.

The analyses with the registration form have already lead to several changes in the studied nursing home: throw rugs have been removed as much as possible, and a new registration form has been developed, in which the severity of dementia and the use of physical restraints as a possible cause of the incident can be registered. All information is stored in a database, which facilitates the preparation of periodical

reports and the performance of specific analyses. We expect this approach to lead to a more effective and extensive use of the available information on the incident reports and thus to a decrease in number of (serious) incidents.

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Chapter 8. General discussion

The aim of this thesis was to study the survival and the natural course of dementia in patients with dementia after admission to a psychogeriatric Dutch Nursing Home. We hypothesized that the great variation in survival time after admission could at least partially be explained by differences in patient characteristics: for instance, the age at admission varied between 52 and 93 years, and for some patients dementia was the only disease they had, while others suffered from many diseases; some patients were only mildly dependent at admission, while others were severely dependent. The literature provided some information about possible predictors of survival, but this information was scarce and did not pay much attention to possible interactions on the influence on survival between these predictors, for instance between comorbidity and severity of dementia.

Main results

- Patients with dementia have a considerably shorter survival than the non-demented population of the same gender and age: in a 2-year period more than twice the number of patients died than was expected according vital statistics. The nature of the excess mortality was additive rather than multiplicative, which indicated that dementia must be primarily seen as an independent risk factor for death. The excess mortality was especially high during the first months after admission.
- The mortality risk for men was almost twice the risk for women.
- For every year of age the patient was older at admission, the risk of dying increased with 3%.
- The presence of comorbid illness at admission also diminished survival chances. Diseases with the highest risk of dying were pulmonary infection, atrial fibrillation, malignancy, heart failure, diabetes mellitus, and parkinsonism. They increased the risk of dying with 50% - 120%. The risk of dying in stroke patients with a pulmonary infection was very high.
- Behavioural problems as measured with a Dutch behavioural rating scale (the BOP = Rating Scale for the Elderly) decreased survival chances. Items with the most prognostic value were "needs help when walking", "occupied in useful activity", "restless at night", and "utters physical complaints". Patients with much impairments on these items had an about 50% higher risk of dying, compared with patients with no impairment on these items. The BOP-subscales with the most prognostic value were Physical Invalidity, Apathy, and Depression.
- After adjusting for gender, age, comorbidity and behavioural items, prognosis did not differ between multi-infarct dementia patients and Alzheimer dementia patients.

- The prognostic information of comorbidity was largely independent from the severity of dementia as measured by the behavioural rating scale.
- The resulting prognostic model, which used all this prognostic information, reliably identified patients with a very poor and with a very favourable prognosis: 10% of all patients had a predicted 2-year survival chance below 20%, and about 16% had a predicted 2-year survival chance above 80%. The results were used for the design of an easily applicable prognostic chart for estimating survival chances in individual patient profiles.
- The severity of the dementia as measured with the Dependency-subscale of the BOP increased during the stay in the Dutch Nursing Home. The patients could be categorized as mildly, moderately, severely demented, or death. On average, about 65% of the patients remained in the same category after a 6-months time period. Most patients became gradually more dependent over time, although there were also patients who remained stable in a 3-year period. Improvement occurred only seldom, mostly in the first half year after admission, and was almost always temporary.
- Fall incidents, which sometimes cause fractures and thus influence prognosis, occurred on average 4 times per patient per year. The risk of falling was higher for men, increased with severity of dementia and physical impairment, but decreased again for the very severely dependent patient. The risk of falling was especially high just after admission, or after transfer from the observation ward to one of the eight nursing wards.

The relevance of knowledge of prognosis for everyday practice.
The results of our study enable us to get a better knowledge of the prognosis of dementia patients. This can be used for decision-making, as well within, as outside the walls of the Dutch Nursing Home. We will discuss this in more detail.

Before admission
Many patients with dementia live at home, especially when the dementia is mild (see also the Introduction). If the dementia becomes more severe and if more behavioural problems occur, the burden on the caregivers increases, and additional, often professional, care has to be organized. Usually in this stage contact has been sought with the general practitioner, a specialist, or the RIAGG (Regional Institute for Ambulant Mental Health Care). They make an assessment of the patient's situation, they evaluate the burden on the caregivers and their tolerance, and the urgency of the situation. Then they decide whether it is necessary to examine the patient more

thoroughly, or whether substitution care, day care, night admission, a temporary, or a definite admission must be advised. The moment of admission is largely determined by a distorted balance between the burden for the caregivers, their capacities and their tolerance. Some situations need a direct admission to a Dutch Nursing Home. If the situation is not urgent and the patient's prognosis is not too poor, it is useful to discuss whether the burden for the caregivers can be relieved by day care or night admission. Uncertainty about the length of survival can be a major barrier to give for instance hospice care at home [1]. Giving a well-founded estimation of the patient's prognosis to the caregivers (e.g. the 3-months survival chance is less than 50%), can make that the caregivers are willing and able to keep the patient at home.

After admission

Once the patient is admitted to the Dutch Nursing Home, there are also many situations in which a decision has to be made in which this patient is involved. These can be purely medical, or non-medical. Decision problems can be discussed with patients who are mildly demented. Alas, for most demented patients admitted to a Dutch Nursing Home a valid discussion about the problem is impossible. The possible wish of the patient can be deduced from statements made earlier (if possible, written statements), from information from close relatives (which must both be interpreted cautiously), or together with the multidisciplinary team that is responsible for the daily care of the patient; such a team usually can observe how the patient experiences his (quality of) life. Judgments about their quality of life are best based on direct observations rather than on generalisations [2]: standardized criteria or algebraic equations are not available [3]. Because in the majority of cases the purpose of treatment is to improve or maintain the quality of life, in most circumstances patients in a psychogeriatric Dutch Nursing Home get the same medical treatment as non-demented patients in a hospital or at home: a mildly demented patient with a pneumonia is treated with antibiotics, a patient who is able to walk but has fallen and shows signs of a hip fracture is directly sent to hospital and will be operated, and an iron deficiency will be supplemented in a moderately demented, active patient. There are only short multidisciplinary discussions about these decisions: an active approach is the preferred option. That decisions can also be less straightforward, is shown in the following examples:

> Patient A is an 80-years old, mildly demented woman with diabetes mellitus, who has been increasingly suffering from severe pain in her left hip during the last six months. Walking

becomes increasingly difficult, and sometimes even hazardous. Adequate pain medication becomes also difficult. Eight years ago she had got a total hip replacement on her right leg, because of osteoarthritis.

Patient B is a 75-years old, moderately demented man, who had a tumour in the neck. A biopsy was performed and the cause appeared to be a non-Hodgkin lymphoma. He received radiotherapy, but there was a recurrence within two months. The radiation sessions were very distressing for the patient.

The treatment options (hip surgery, radiation or chemotherapy) can be of considerable burden for the patient. The two-year survival chance according to the prognostic model in Chapter 5 for Patient A is about 65%, and it seems worthwhile to offer her a total hip, while it can increase her quality-of-life during many years. Patient B had a two-year survival chance of only 20%. Without the malignancy this chance would be about 50%. Chemotherapy seemed not appropriate anymore, but palliative radiotherapy might increase his quality-of-life for a short period. A similar evaluation of the possible consequences of the treatment options can be necessary in the two patients in the introduction: the 85-years old mildly demented woman who had a senile cataract (cataract extraction) [4], and the 80-years old man with a vague pain in the abdominal region, loss of appetite, weight loss, and increasing anemia (endoscopy).

Decisions about starting or withholding treatment are especially difficult if they can not be discussed appropriately with the patient, or if the patient disagrees or seems to disagree with the treatment proposed by the physician. In such a situation the possible inconvenience and the expected benefit of that treatment must be weighted against the patient's right of self-determination. If a treatment causes little inconvenience and is expected to improve the health or the subjective well-being of the patient substantially, refusal of a treatment can only be respected if the patient is fully competent (which means that he is able to give good and objectively valid reasons for his refusal). If the patient is not entirely competent and can not overview the consequences of a treatment, most physicians will do what they themselves think what is in the patient's best interest. For instance, a moderately demented, mostly happily-looking patient with a pneumonia will be treated with antibiotics, if necessary by intramuscular injections if he refuses to take them by mouth.

If the treatment becomes more invasive or aggressive, and for instance implies a hospital admission, or if the expected benefit becomes doubtful, the right of self-determination of the patient becomes more important. If in case the patient with pneumonia had been severely demented, psychosocial aspects may interfere more with

the decreased medical usefulness of giving antibiotic treatment, and intramuscular injection is less evident. A more extensive description of the relation between treatment and the competence and autonomy of the patient can be found in a report about life-shortening treatment in severe dementia [5]. Recently the BOPZ (Wet Bijzondere Opneming in Psychiatrische Ziekenhuizen, a law which describes the rights of mentally incompetent patients regarding admission and treatment), has come into force, which provides that a physician can only treat the patient after permission from a trustee of the patient [6]. Treatment of a patient who refuses treatment, is only permitted in emergencies or life-threatening situations.
A decision analysis can be helpful in arriving at the best decision: it forces the physician to structure the problem, to estimate the chances and risks of the several options, and to define the outcome he is interested in [7]. The medical usefulness can thus be better evaluated. Knowledge of the prognosis is thus very important. For instance, if a patient has relatively high survival chances according to our prediction model, the chance is great that the length of the improved quality-of-life outweighs the initial burden and inconvenience. If life expectancy is very low, and it is not expected that a poor quality-of-life will improve (considerably), withholding treatment is justified. Informing the family is very important in this case: sometimes the relatives have other expectations, for instance when they think the patient may improve to the same level as they were before the intercurrent disease took place.

Knowledge of prognosis is also important in non-medical decisions. It can help close relatives if they want to make special adjustments to their house to make it possible that their demented family member visits them. Sometimes these relatives might think that these adjustments are not useful anymore, while the patient might be staying alive for several more years; on the other hand, a well-founded advice that the prognosis is poor can prevent the relatives from making (financial) efforts they might not have made otherwise. Knowledge of prognosis can also be important for economic reasons: adjustments or treatment are sometimes not appropriate anymore if it is known that the prognosis is very poor, with or without treatment.
Knowledge of prognosis is also important in decisions about transfers to another ward, or to another Dutch Nursing Home. Because these transfers can cause additional excess mortality and increase the risk of falling, they are only justified if the patients' survival chances are high enough that they at least have the chance to get accustomed to the new environment, and if other reasons are present (for instance,

there are special wards for mildly, for moderately, and for severely demented patients; the other Dutch Nursing Home is much easier within reach for the key relatives).
Many patients coming from a hospital have a dwelling catheter, sometimes because of incontinence. For some causes, patients can become continent again with some training; this needs special efforts, but if the patient has favourable survival chances, and the cognitive functions are relatively preserved, such a training can be worthwhile and prevent the patient from wearing diapers for a long period.
For the Dutch Nursing Home physician, and also for the other members of the staff, knowledge about the natural course of the dementia in terms of symptomatology or severity, and the prognosis regarding ADL-related activities and the ability to walk can also be very helpful. For example, orthopedic shoes might not be indicated if the patient is not expected to walk anymore. The natural course and the methodology how to describe the development of dementia over time has been paid attention recently [8]. The course of dementia after admission to a Dutch Nursing Home has also been extensively described by Ekkerink [9]. Health planners might be interested in the expected increase in dependency in relation to the amount of help needed for daily care in a Dutch Nursing Home. Gagnon for instance has investigated the "non-bedridden survival" [10], and he found that one year after admission to a neurological ward 69% of the patients still was not bedridden, and 44% after two years. Because 15% were lost to follow up, the exact figures must be interpreted cautiously.

Formal medicine
Knowledge of life-expectancy can also be used in protocols regarding diagnosis and treatment. Often these protocols are only individualized with respect to the absence or presence of specific symptomatology, and do not account for other patient characteristics. As an example, patients with diabetes mellitus often receive a diet in order to prevent short and long-term complications, and this is not discussed with the patient. If he has a poor prognosis according to the prognostic chart, the physician might consider to focus the regulation of the blood sugar on the prevention of short-term complications. This could have as a consequence that daily insulin injections are not necessary anymore in a number of patients.

Methodological considerations

Data collection
Data were collected by means of a retrospective chart review. This enabled us to follow up patients during many years after their admission to the Dutch Nursing

Home. This method had the disadvantage that several topics we were interested in could not be handled as thoroughly as possible, because these topics were not to be registered systematically. Some of these will be discussed in detail. We were not able to determine the score on the *Hachinski Scale*, often used for discrimination between Senile Dementia of the Alzheimer's Type, multi-infarct dementia, and a mixed dementia [11]. The scale contains 13 items. Although the scale has its limitations, and a "modified Hachinski score" is proposed [12], a comparison between the type of dementia according to this scale and to the diagnosis made by the Dutch Nursing Home physician would have been interesting. Several items could not be reliably scored in our study, or could not be found in the patient's record at all. Myoclonus and *extrapyramidal signs and symptoms*, which form the base of the existence of subgroups within Alzheimer's disease according to Mayeux [13], were not registered systematically. *Severity of comorbid illness*, such as for instance the number and the stage of pressure sores, could also not be reproduced always.

To assess *cognitive functioning* the Dutch Nursing Home used a standardized battery of psychological tests. The contents of this battery changed in August 1985. Furthermore it could not always be determined why one, more or all tests in a patient were missing. The BOP (Rating Scale for the Elderly) was used to describe the behavioural characteristics of the dementia patients. This scale has been used in many Dutch Nursing Homes since its introduction in 1971 [14], and the validity of this scale has been demonstrated in a review ten years later [15].

Several topics about events after the observation period which were not investigated yet, were the incidence of intercurrent diseases and their influence on survival and dependency, and the course of dementia-related behavioural items with rather direct practical implications such as the amount of help needed when walking, when dressing, or when eating.

A more formal description of the course of dementia needs a regular assessment of symptomatology. More uniformity in behavioural rating scales and in staging severity of dementia is desirable in order to make a better comparison of results possible. Several authors have described the SDAT in stages, based on severity or occurrence of symptoms [16,17,18]. These stages more or less assume that there are symptoms which inevitably appear somewhere in the course, and there is more or less a uniformity in the sequence they appear. Thal for instance found that SDAT-patients first developed memory disturbances, about one year later they developed language disturbance, apraxia, personality changes, and disorientation [19]. Information about

the time intervals between their first appearance might be of help in making more well-founded estimates of rates of further progression. This information might also of help for the indication of subgroups.

Modelling

The performance of the model in Chapter 5, which used the prognostic information from age, gender, comorbid illness and severity of dementia, can possibly be improved by incorporation of other patient characteristics such as aphasia, apraxia, scores on psychological tests into the model, investigation of interactions between variables in their effect on mortality, describing the severity of coexisting illness, and differentiating between old and recent strokes (and myocardial infarctions). Because our data were gathered retrospectively, there were many missing values on the many variables mentioned just above, and would have forced us to use several subsets of patients: for instance, many psychological test were only performed since August, 1985.

The estimation of survival chances in this study was based on patient characteristics from the first 6 weeks after admission. In this period a patient in Stadzicht is evaluated socially, medically, psychologically, and functionally. Thereafter many changes and events can take place: patients become on average more dependent over time (Chapter 6), and they fall on average four times a year, with the risk of getting a fracture (Chapter 7). Besides that, many other illness can be present during the stay in the Dutch Nursing Home. It is obvious that this can considerably influence the survival chances of the patients.

In theory, the proportional hazards model can cope with such "changes in prognostic status". Probably this will increase the predictive power, and from a scientific point of view it may considerably contribute to the insight into the relation between dementia, (intercurrent) comorbidity, (changes in) functional status, and life expectancy. In practice, such a model would become very difficult to interpret for the Dutch Nursing Home physician. If he wants to know the patient's prognosis, it would be much easier and more realistic to do this on a model based on data from the patient's situation at that moment. In that case it could be interesting whether variables describing the rate of progression during the first year improve the predictive probabilities. Preliminary analyses in our cohort showed that this rate of progression had hardly any prognostic value. This would confirm results of Drachman in outpatients with dementia [20]. Unfortunately further analyses could not be realized within the framework of this thesis.

Generalization

Our results are based on data from one Dutch Nursing Home and therefore not automatically applicable to other institutions. Survival can be different from other Dutch Nursing Homes because of differences in patient characteristics. For instance, overall figures will be higher if a Dutch Nursing Home admits only mildly demented patients, or only women. Patient characteristics of our study population did not differ essentially from some other studies in the Netherlands [21,22].

Our survival figures differ from those of Koopmans [23], who found in 890 patients admitted to another psychogeriatric Dutch Nursing Home an overall two-year survival rate of 43%. According to Koopmans, these differences could be explained by differences in the definition of the presence of comorbidity at admission, in the proportion of patients with multi-infarct dementia, the age at admission, and the fact that they only analyzed patients who were admitted permanently. The latter two explanations are unlikely: the mean age at admission in the 2 studies differed only 0.4 year. A reanalysis of our data, which excluded patients who were discharged, resulted in a two-year survival rate of 54%.

The prediction model adjusts for the patient characteristics age, gender, comorbidity, and severity of dementia, and should therefore reliably predict outcome in other Dutch Nursing Homes, at least if it can be assumed that the variables in the model are scored in the same way. This will not be a problem for gender and age, but difficulties can arise in establishing diagnoses such as a malignancy or parkinsonism. If a disease is present in reality, but not as such recognized or searched for in Stadzicht, the model will give an overestimate of survival chances. Scoring problems can also arise for the behavioural items, although the reliability of the BOP-items seems reasonable [24].

Generalization of our results to all dementia patients is probably more hazardous. Patients outside the Dutch Nursing Home do often not receive the same 24-hour care and supervision, and therefore are more easily prone to isolation, inactivity and malnutrition than might be expected according to the severity of their dementia. On the other hand, the behavioural items we used in our study might not be appropriate to assess the severity of dementia in a less advanced stage: all scores will be indicating no impairment - the so-called floor-effect of the scale -, but the model does not adjust for capacities which are lost in most patients admitted in a Dutch Nursing Home, but still might be present for those who are not admitted, such as driving and shopping. It would be interesting to evaluate whether our prognostic chart reliably predicted survival chances outside the walls of the Dutch Nursing Homes.

Nevertheless, we think that our approach to estimate survival chances on the base of patient characteristics (and the resulting prognostic chart), can also be used for other diseases in Dutch Nursing Homes, such as Parkinson's disease. Decisions have to be made by the physician in individual patients, and they have the right on an individual evaluation of chances and risks.

Future

Because of future demographic developments (such as an increased life expectancy in the population and henceforth an increased number of patients above 65 years), it is expected that the number of patients with a diagnosis of severe dementia will increase from 100 000 nowadays to 150 000 patients in the year 2010 [25], without patients with cerebrovascular disease who also have dementia but are not diagnosed as such. The possibly increased diagnostic and therapeutic possibilities are not likely to have a large effect on this increase [25]. If we want to maintain the quality of care for the demented elderly on the level of today, there will be an increase in health care demands from this group of patients.

Furthermore, there are many developments in the care for the demented elderly: Dutch Nursing Homes want to spread their vision about care outside the walls of the institution. There is a tendency to keep the demented patient in his own environment as long as possible. Day care has proven to be very useful in this respect by decreasing the pressure on caregivers [26]. There is also an increasing number of Dutch Nursing Homes which provide night care. Many homes for the elderly provide substitution care, which implies that their demented residents receive Dutch Nursing Home care such as a day structuring and a structured care plan. A Dutch Nursing Home physician provides professional support in case of dementia-related behavioural problems, so that the patients can stay longer at home.

The continuity and the quality of Dutch Nursing Home care probably increases lifespan as compared to care at home: acute illness is diagnosed rather quickly; there is a daily observation of water- and food-intake, and changes are reported; physical therapy for the prevention of for instance contractures is more easily prescribed. On the other hand, admission to a Dutch Nursing Home is often distressing for the patient, regarding the finding that the mortality and the risk of falling are especially high the first period after admission.

If the developments continue the way they are going nowadays, it is expected that many patients will be admitted to the Dutch Nursing Home in a later stage of the

dementia. In Chapter 3 we already calculated how an increase in severity at admission can change the expected two-year survival. Such a new policy then implies that more patients with dementia will be admitted, but during a shorter time.
Many dementia patients can not live without professional care, and can not decide anymore what they want or what they would have wanted. This makes it even more important that decisions about day care, substitution care, and admission to a Dutch Nursing Home, and also about surgery or admission to a hospital, are made on the base of a well-founded prognosis. We think that the results of this study have given a limited, but useful contribution to prognostication in patients with dementia. Further research is needed to establish the validity of our results, and to evaluate whether new developments in the treatment of dementia or in the organization for the disabled elderly have an influence on the quality-of-life and the life expectancy of dementia patients.

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Summary

The aim of this thesis was to analyze the prognosis of patients with dementia after admission to a Dutch Nursing Home. The first part dealt with the survival after admission and tried to find the patient characteristics with the most predictive value. The second part aimed to give a description of two aspects related to the natural course of dementia: the dependency and risk of falling.

In *Chapter 1* the available literature on survival in dementia was summarized. There were no reliable data on survival after onset of dementia or after first contact with medical services. People with dementia in outpatient clinics and nursing homes had two-year survival rates of 75% (range 60% - 95%) and 50% (range 30% - 65%) respectively. Differences in survival between patients with Senile Dementia of the Alzheimer Type (SDAT) and multi-infarct dementia (MID) were small. Women in (mostly Dutch) nursing homes had a better prognosis than men (two-year survival rates 60% versus 40%). Dementia patients had a considerable excess mortality compared to the vital statistics. There was no evidence for an improvement of survival rates over the last decades. Recommendations for future studies were made.

Several of these recommendations were operationalized in the following four chapters. Survival data from 606 dementia patients admitted to Stadzicht, a psychogeriatric Dutch Nursing Home in Rotterdam, were analyzed in a historically prospective 8-year follow up.

Chapter 2 started with a description of the procedure which dementia patients had to undergo before they could be admitted to a Dutch Nursing Home in the region of Rotterdam during the study period. It was followed by a general description of the population under study. The two-year survival rate after admission was 55% overall, and 60% for the 437 women and 39% for the 169 men. Patients with SDAT had higher two-year survival rates than those with multi-infarct dementia (57% versus 41%). High physical impairment, inactivity, dependency as measured on the BOP (Beoordelingsschaal voor Oudere Patiënten), a Dutch behavioural rating scale for elderly patients, and comorbidity had an adverse affect on survival. Diseases with the lowest two-year survival rates were myocardial infarction, heart failure, atrial fibrillation, parkinsonism, pulmonary infection, anemia, pressure sores and malignancies. The mortality rates of dementia patients were higher than those of the general population, especially during the first months after admission. This excess mortality in dementia patients was better described by an additive than by a multiplicative factor, suggesting that dementia can primarily be regarded as an independent, competing mortality risk.

In *Chapter* 3, special attention was paid to the prognostic value for survival of the BOP, the Dutch behavioural rating scale containing 35 items, which take part of one or two of the six subscales. The two-year survival rate for the entire cohort with available data on this scale (N=569) was 56%. The 459 women had a two-year survival rate of 62%, and the 110 men had a two-year survival rate of 40%. Items indicating physical impairment, dependency and apathy had most prognostic value. Items measuring aggressive or depressive behaviour, and cognitive impairment were less predictive. These results were confirmed in a multivariate proportional hazards analysis. A prognostic model with age, gender and 5 behavioural items ("needs help when walking", "occupied in useful activity", "restless at night", "utters physical complaints", and "socializes with other patients") was constructed. The model gives a predicted survival chance of less than 20% or more than 80% in 80 of the 569 patients. When adjusted for the variables in the model, previous residence had no prognostic value anymore. Possibilities for further work in this area of research were discussed.

In *Chapter 4*, the relation between comorbidity and survival was investigated. Parkinsonism, atrial fibrillation, pulmonary infection, and malignancies were powerful predictors: they more or less doubled the mortality chances. Stroke patients with a pulmonary infection had a particularly poor prognosis. More severely demented patients had more comorbidity than less severely demented patients, but the impact of comorbidity on survival did not depend on severity of dementia. Patients coming from a hospital had more comorbidity and were more severely demented than patients coming from home, but this did not modify the effects of age, gender, and comorbidity in a multivariate survival model. It was concluded that comorbidity and severity of dementia independently influence mortality. Thus a better prognostic judgment is obtained from their combination than from each separately. This finding was analyzed further in the next chapter.

In *Chapter 5*, the survival chances were estimated by evaluating the joint information of the several kinds of patient characteristics used in the previous three chapters by means of the proportional hazards regression model. The resulting model is translated in an easily applicable prognostic chart. This model reliably identified many patients with a very poor and a very favourable prognosis: from the 569 patients, 64 patients had a predicted two-year survival chance below 20%, and 110 patients a chance over 80%. As in the previous chapter, comorbidity had a considerable impact on survival. Particularly patients with a pulmonary infection and a previous stroke had a poor prognosis (hazard ratio 34.1; 95% CI 14.6 - 79.8). Pulmonary infection, atrial fibrillation, malignancy, heart failure, diabetes mellitus, and parkinsonism

were the other comorbid conditions with much predictive value (hazard ratio varying between 1.5 and 2.2). From the behavioural items of the BOP the amount of 'help needed when walking' was the most informative predictor (hazard ratio 1.3). Age (hazard ratio 1.03 per year) and male gender (hazard ratio 1.8) had also independent predictive value. After adjustment for these prognostic factors patients with a multi-infarct dementia had the same prognosis as patients with SDAT.
It was concluded that the prognostic model and accompanying chart can be informative in estimating individual survival chances for demented nursing home patients.
In *Chapter 6*, the course of dependency in dementia patients was described and differences in this course between subgroups were investigated. For this purpose data were used from the 397 patients who were admitted to Stadzicht between 1984 and 1988. The BOP was regularly filled out to assess the degree of dependency over time: patients could be mildly, moderately or severely dependent. The development of dependency over time was studied using a probabilistic multi-state model. At admission 41% of the patients were mildly, 42% moderately, and 17% severely dependent. After two year only 11% of the patients were still mildly dependent, 20% moderately and 19% severely dependent; 50% had died. It was concluded that there was a shift towards more dependency over time. Improvement and deterioration from mild to severe dependency within half-year periods was seldom. No major differences in patterns of deterioration between gender, age or type of dementia were observed.
In *Chapter 7*, the number and nature of falls in Stadzicht were analyzed. 1343 Falls were reported over a two year period in 240 patients. This implies a rate of about 4 falls per personyear. Only 1 out of 4 patients had no fall within one year. The risk of falling was especially high shortly after admission and after transfer to another ward. The risk increased with severity of the dementia and physical impairment, and decreased for the very severely demented or physically handicapped patient. Men had two times the risk of falling of women. Most incidents were quite harmless, but 22 hip fractures, 5 wrist fractures and 6 other fractures were reported. The most important causes for falls were "inadequate (use of) materials, stumbling or slipping" (17%) and "gait and equilibrium disturbances" (16%).
The discussion (*Chapter 8*) gave a short summary of the main results, and paid attention to the possible relevance of the knowledge about the prognosis for everyday practice. This prognosis is one of the aspects which the Dutch Nursing Home physician uses in medical or in non-medical decision-making. Special attention was paid to decisions about starting or withholding treatment in view of the decreased cognitive functioning and the decreased quality-of-life many demented patients

have. Furthermore the problems which are often related to a retrospective chart review were described: it prohibited several patient characteristics to be analyzed on their prognostic value. Thereafter some remarks were made about the generalization of our results to other Dutch Nursing Homes and to demented patients in general. Finally the results were put in relation with future developments.

Samenvatting

Het doel van dit proefschrift was een onderzoek te verrichten naar de prognose bij patiënten met dementie na opname in een verpleeghuis. Het eerste deel beschrijft de overleving na opname en tevens welke patiëntkarakteristieken een voorspellende waarde hebben met betrekking tot de overlevingskansen. In het tweede deel worden twee deelgebieden die bij het beloop van de dementie van belang zijn, beschreven: de hulpbehoevendheid en het valgevaar.

In *Hoofdstuk 1* wordt de beschikbare literatuur over de prognose bij patiënten met dementie samengevat. Er bleken geen betrouwbare gegevens te zijn met betrekking tot de overleving na het begin van de dementie en na de eerste contacten met het medische circuit. Demente patiënten die een polikliniek bezochten of die verbleven in een verpleeghuis hadden twee-jaar overlevingscijfers van 75% (range 60% - 95%) en 50% (range 30% - 65%). De verschillen in overleving tussen patiënten met een seniele dementie van het Alzheimer type (SDAT) en multi-infarct dementie waren gering. In (voornamelijk Nederlandse) verpleeghuizen gold dat vrouwen een betere overleving hadden dan mannen (twee-jaar overlevingscijfers van 60% tegen 40%). Vergeleken met bevolkingsstatistieken was er bij dementiepatiënten een duidelijke oversterfte. Er kon geen bewijs gevonden worden voor een verbeterde levensverwachting voor demente patiënten gedurende de laatste tientallen jaren. Er werden aanbevelingen voor verdere studies gedaan.

Verschillende van deze aanbevelingen zijn uitgewerkt in de volgende vier hoofdstukken door middel van een longitudinaal onderzoek met een follow-up van maximaal 8 jaar. Als basis hiervoor gelden overlevingsgegevens van 606 patiënten die opgenomen werden in Stadzicht, een psychogeriatrisch verpleeghuis in Rotterdam.

In *Hoofdstuk 2* wordt beschreven welke mogelijke wegen een patiënt met dementie in de regio Rotterdam moest doorlopen voordat hij kon opgenomen worden in het verpleeghuis. Daarna wordt de studiepopulatie nader beschreven aan de hand van kenmerken bij opname. Het twee-jaar overlevingscijfer voor het gehele cohort was 55%, 60% voor de 437 vrouwen en 39% voor de 169 mannen. Patiënten met SDAT hadden een hoger twee-jaar overlevingscijfer (57%) dan die met multi-infarct dementie (41%). Hogere lichamelijke invaliditeit, inactiviteit en hulpbehoevendheid zoals gemeten aan de hand van de BOP (Beoordelingsschaal voor Oudere Patiënten), een in Nederland veel gebruikte observatieschaal, en de aanwezigheid van comorbiditeit (bijkomende aandoeningen) hadden een negatief effect op de overlevingskansen. Aandoeningen met de laagste twee-jaar overlevingscijfers bij univariate analyses waren het hartinfarct, decompensatio cordis, atriumfibrilleren, M. Parkinson (of par-

kinsonisme), een luchtweginfectie, anemie, decubitus en maligniteiten. Verder bleek dat de sterftecijfers van dementiepatiënten veel hoger waren dan die van de algehele bevolking; dit was met name het geval in de eerste maanden na opname. Deze oversterfte bleek beter verklaard te kunnen worden door de dementie te beschrijven als een additieve dan als een multiplicatieve factor. Dit wijst er op dat de dementie met betrekking tot overlijden met name beschouwd moet worden als een onafhankelijke risicofactor.

In *Hoofdstuk 3* wordt verder ingegaan op de prognostische waarde van de in Nederland veel gebruikte gedragsobservatieschaal de BOP. Deze bestaat uit 35 items, die deel uit maken van 1 of 2 subschalen. De twee-jaar overleving van de 569 personen waarvoor gegevens van de BOP beschikbaar waren is 56%. De 459 vrouwen hadden een twee-jaar overleving van 62%, en voor de 110 mannen was dit 40%. Items met betrekking tot lichamelijke invaliditeit, hulpbehoevendheid en inactiviteit hadden de meeste prognostische waarde. Voor items met betrekking tot agressiviteit en depressief gedrag, of psychische invaliditeit was deze waarde afwezig of slechts gering. Deze resultaten werden bevestigd in een multivariate proportional hazards analyse. Het bleek dat een prognostisch model met als variabelen leeftijd, geslacht en 5 items van de BOP - schaal (hulp bij lopen nodig, zinvol bezig zijn, onrust 's nachts, uiten lichamelijke klachten, en omgaan met andere bewoners) een aanzienlijke bijdrage kon leveren aan het schatten van overlevingskansen in patiënten met dementie. Het model voorspelde een twee-jaar overlevingskans van minder dan 20% of meer dan 80% in 80 van de 569 patiënten. De verblijfplaats voor opname in het verpleeghuis had geen prognostische waarde voor overleving meer nadat gecorrigeerd was voor de 7 variabelen van het model.

Aan de hand van soortgelijke analyses wordt in *Hoofdstuk 4* ingegaan op de relatie tussen de aanwezigheid van comorbiditeit en kansen op overleving. Uit multivariate analyses bleek dat M. Parkinson (of parkinsonisme), atriumfibrilleren, een luchtweginfectie, en maligniteiten gepaard gaan met een slechte prognose: ze verdubbelden min of meer de kans op overlijden. De slechtste prognose hadden personen met de combinatie van (status na) CVA en een luchtweginfectie. In het algemeen bleek dat ernstig demente patiënten meer comorbiditeit hadden dan de relatief minder ernstig demente patiënten. De invloed van de comorbiditeit op de overlevingskansen was echter onafhankelijk van de ernst van de dementie. Patiënten die afkomstig waren uit het ziekenhuis hadden meer comorbiditeit en waren in het algemeen ernstiger dement dan diegenen die van huis kwamen. Dit had echter geen effect op de invloed van leeftijd, geslacht, en comorbiditeit in een multivariaat prognostisch model. Omdat waarschijnlijk was gemaakt dat comorbiditeit en de ernst van dementie een

onafhankelijke invloed had op de prognose, werd gesteld dat een prognostische uitspraak beter gedaan kan worden aan de hand van beide kenmerken dan aan de hand van elk kenmerk apart. Dit gegeven wordt verder uitgewerkt in het volgende hoofdstuk.
In *Hoofdstuk 5* worden de overlevingskansen geschat op basis van de gecombineerde prognostische informatie zoals deze al geanalyseerd is in de vorige drie hoofdstukken met behulp van het proportional hazards model. Het resulterende model is zo bewerkt dat hiermee op eenvoudige wijze een prognostische scorekaart ingevuld kan worden en een prognose afgelezen kan worden. Het bleek dat het resulterende model vele patiënten met een hele slechte en een hele goede prognose kon onderscheiden: van de 569 patiënten hadden er 64 een voorspelde twee-jaar overleving van minder dan 20%, en 110 patiënten een voorspelde twee-jaar overleving van 80% of meer. Zoals al uit eerdere hoofdstukken bleek, had de comorbiditeit in dit model een duidelijke invloed. De slechte prognose voor CVA - patiënten met een luchtweginfectie werd bevestigd. Een luchtweginfectie bij niet-CVA patiënten, atriumfibrilleren, een maligniteit, hartdecompensatie, diabetes mellitus, en M. Parkinson (of parkinsonsisme) verhoogden de sterftekansen met 50% - 120%. Het item 'hulp bij lopen nodig' was het prognostisch meest informatieve item van de BOP - schaal. Leeftijd en geslacht behielden hun onafhankelijke prognostische waarde. Na correctie voor al deze variabelen in het model hadden patiënten met een multi-infarct dementie dezelfde prognose als patiënten met een seniele dementie van het Alzheimer type. Er werd geconcludeerd dat een dergelijk model informatieve waarde heeft bij het schatten van de prognose bij individuele verpleeghuispatiënten met dementie. De verpleeghuisarts dient zelf de absolute waarde hiervan in te schatten aangezien hij normaliter nog andere informatie heeft over de patiënt.
In *Hoofdstuk 6* wordt het beloop van de hulpbehoevendheid bij patiënten met dementie beschreven. Verder is er onderzocht of er verschillen in beloop tussen patiëntgroepen aanwezig zijn. Het onderzoek richt zich op de patiënten die tussen 1984 en 1988 opgenomen werden. Om het beloop van de hulpbehoevendheid te beschrijven, zijn de verschillende scores op de gelijknamige BOP - subschaal, welke na opname regelmatig ingevuld zijn, geanalyseerd. Aan de hand van die score werden de patiënten beoordeeld als begeleidings-, verzorgings-, of verpleegbehoeftig. Het beloop in de tijd werd bestudeerd aan de hand van een probabilistisch meerstadia model. Bij opname waren 41% van de patiënten begeleidingsbehoeftig, 42% verzorgingsbehoeftig, en 17% verpleegbehoeftig. Twee jaar later was nog slechts 11% begeleidingsbehoeftig, terwijl 20% verzorgingsbehoeftig was, en 19% verpleegbehoeftig. De overige 50% waren overleden. Het was duidelijk dat de

hulpbehoevendheid toenam met de tijd. Er trad slechts zelden verbetering op. Een overgang van begeleidingsbehoeftigheid naar verpleegbehoeftigheid in een periode van een half jaar was eveneens zeldzaam. Er waren geen grote verschillen in achteruitgang na onderverdeling voor geslacht, leeftijd, of type dementie.
Hoofdstuk 7 geeft een analyse van de aard en het aantal van valincidenten in het verpleeghuis. In twee jaar zijn in Stadzicht 1343 valincidenten gemeld bij 240 patiënten. Dit betekent een frequentie van 4 vallen per persoon per jaar. Slechts een op de vier patiënten was binnen een jaar na opname nog niet gevallen. De kans op een valincident was vooral hoog vlak na opname of vlak na overplaatsing naar een andere afdeling. De kans op vallen nam toe bij toenemende hulpbehoevendheid en lichamelijke invaliditeit zoals gemeten op de BOP - schaal, en nam weer af bij ernstige hulpbehoevendheid of lichamelijke invaliditeit. De kans op vallen was voor mannen twee keer zo groot als voor vrouwen. De meeste incidenten hadden geen ernstige gevolgen. Desondanks traden er bij de bovengenoemde patiënten 22 heupfracturen, 7 polsfracturen en 6 andere fracturen op. Als belangrijkste oorzaken voor de valincidenten werden genoemd "ongeschikt (gebruik van) materiaal, struikelen of uitglijden" (17%) en "loop- en evenwichtsstoornissen (16%).
De discussie van *Hoofdstuk 8* vat kort de resultaten weer, en schenkt aandacht aan het mogelijke praktische nut van de kennis over de prognose in de dagelijkse praktijk, zowel bij het nemen van beslissingen op medisch als op niet-medisch terrein. Daarnaast wordt ingegaan op de rol van de prognose bij (niet)-behandelbeslissingen in relatie tot andere factoren die spelen bij veel patiënten met dementie, zoals het verminderd cognitief functioneren en de verminderde kwaliteit van leven. Verder wordt nog ingegaan op methodologische aspecten zoals de aard en kwaliteit van de gegevens bij retrospectief statusonderzoek, waardoor sommige patiëntkenmerken niet kunnen worden onderzocht op hun prognostische waarde. Verder worden enkele opmerkingen gemaakt naar de generaliseerbaarheid van de gegevens naar andere verpleeghuizen en naar dementie in het algemeen, en worden relaties gelegd in het licht van toekomstige ontwikkelingen.

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Curriculum Vitae

Pieter van Dijk werd geboren op 18 oktober 1960 in Tegelen. Hij bracht zijn jeugd door in Panningen. Na het Gymnasium - beta te doorlopen hebben aan het Thomascollege te Venlo, begon hij in september 1979 aan de studie Geneeskunde aan de Katholieke Universiteit van Nijmegen. In februari 1987 behaalde hij aldaar het artsexamen. In dezelfde maand begon hij als AIO (assistent-in-opleiding) aan het Instituut Maatschappelijke Gezondheidszorg van de Erasmus Universiteit (hoofd: Professor dr PJ van der Maas); later werd hij gedetacheerd aan het Centrum voor Klinische Besliskunde (hoofd: Professor dr J Lubsen, vanaf 1991 Professor dr ir JDF Habbema). Aangezien zijn hart toch lag bij het praktisch-klinisch werk, begon hij in september 1991 aan de opleiding voor verpleeghuisarts. Het praktische deel van de opleiding volgde hij in de verpleeghuizen het Gulden Huis (opleidster Mevr A Valkhof, arts) en Mariahoeve (opleider Hr T Hooghiemstra, arts; later Hr H Koenders, arts), beide in Den Haag. Het theoretische deel van de opleiding werd gevolgd aan de Vrije Universiteit te Amsterdam (hoofd Prof dr MW Ribbe). Vanaf september 1993 is hij als geregistreerd verpleeghuisarts werkzaam in verpleeghuis Beukenrode te Venray.

Appendix Part 1. The subscales of a Dutch behavioural rating scale for the elderly in a psychogeriatric population

The BOP (Beoordelingsschaal voor Oudere Patiënten), which is translated as "Rating Scale for Elderly Patients", has been used in many nursing homes in the Netherlands for almost 20 years [1]. The value of this scale in daily practice use in nursing homes is largely proven. Furthermore the scale has formed a base for many scientific articles [2]. The BOP contains six subscales, based on results derived from a factor analysis. The subscales can be used for a breakdown in subgroups, for estimating work load [3], (for which purpose also data are taken from the SIVIS - SIG Nursing homes information system [4]), and as prognostic variables for survival [5-7]. For the factor analysis of this study observations were used from 965 somatic and/or psychogeriatric patients, residing in several nursing homes. A few psychiatric elderly patients were included as well. The question we asked ourselves was to what extent the BOP-behavioural rating scale, developed for nursing home patients in general, was relevant for psychogeriatric patients in particular. To answer this question we decided to carry out a factor analysis the same way as was done in the past, but now on our own cohort, containing data of the BOP-scores of 569 patients. The purpose of this analysis was twofold: on the one hand to look for similarities between the subscales in both analyses; on the other hand to explain possible differences by a difference in population, our data concerning only dementia patients.

Material and methods

Patients

Between January 1st, 1982 and January 1st, 1989 606 patients were admitted to the psychogeriatric Centre Stadzicht in Rotterdam, The Netherlands. There were 437 women and 169 men. The mean age at admission was 80.8 year (SD 6.8). The patients were admitted because of dementia.

BOP - Rating scale for elderly patients

All patients were assessed by way of the BOP rating scale on regular intervals. In the analysis, we used the BOP-scores measured for the persons who had a complete assessment at the end of the observation period, about 6 weeks after admission. Data of 569 persons were used. For 37 persons no BOP-scores were available.

Method of structure definition

The factor analysis which was used for the development of the scale, was carried out on 42 items, mainly derived from the Stockton Geriatric Rating Scale [8]. The procedure was based on the "principal axis" method in SAS (Statistical Analysis System), and there were 4 factors drawn. The factors 2, 3 and 4 were rotated according to the varimax standard. For insertion in scale 1 a minimum loading on factor 1 of 0.45 was required. For insertion in one of the other scales a minimum loading of 0.30 on one of the other factors was required [1]. The replication analysis described below was in principle carried out in a similar way, except for the availability of only 35 items instead of 42. For 7 items no data were available. In the original analysis the 35 items were finally placed into 1 or 2 subscales. In total there were 6 BOP subscales.

Results

Frequency distribution of BOP-items

Table 1 shows the frequency distribution on the 35 items. Some items, like item 6 ("needs protection from falling out of chair"), item 11 ("unable to find his way around the ward"), item 17 ("doesn't respond to his name"), item 19 ("weeps easily"), have a very distorted distribution, whereas item 28 ("needs supervision outdoors") scores 1 for almost everyone. Compared with the mean scores on the subscales and the frequency distribution of the original analysis, our patients scored significant higher for Dependency, Aggressiveness and Orientation & Communication. There were also slightly more depressive symptoms [1]. The frequencies on the items Physical Disability and Apathy showed little difference with the original distributions. Moreover, the differences didn't direct clearly to more or less problematic behaviour. When comparing our quartiles of the scores on the different subscales with the ones of the original study about psychogeriatric Dutch Nursing Homes, again no clear-cut differences were found. Apparently the differences in scores are caused by the distinction made between somatic and psychogeriatric patients.

Table 1. Distribution of scores on the 35 items of the BOP (N=569) in percentages.

item	scales	description	score		
			0	1	2
1	Ag	threatens verbally to harm others	65	19	16
2	Ag	accuses others of harming him	49	21	30
3	D	needs help when eating	39	42	19
4	D	incontinent during the day	52	16	32
5	Ag	hits and kicks other patients	76	15	9
6	PD	needs protection from falling out of chair	86	5	9
7	Ag	objectionable during the day	53	22	25
8	De	sad	23	37	40
9	PD	needs help when walking	46	28	26
10	D	does not make himself understood	47	39	14
11	D	unable to find his way around the ward	8	20	72
12	D-OC	doesn't know in which institution he is	7	23	70
13	D-OC	doesn't know any of personnel by name	3	4	93
14	D-OC	doesn't understand others	44	50	6
15	A	doesn't help out on the ward	19	18	63
16	De	utters physical complaints	43	22	35
17	D-OC	doesn't respond to his name	87	12	1
18	D-A	occupied in useless activity	33	34	33
19	De	weeps easily	81	10	9
20	D-A	doesn't socialize with other patients	40	27	33
21	D	urinates and defecates at the wrong place	71	12	17
22	D-A	doesn't help other patients without being asked	26	23	51
23	D	unwilling to do things asked of him	41	54	5
24	A	no privileges to leave the ward	24	52	24
25	D	engages in useless repetitive activity	48	13	39
26	D	makes repetitive vocal sounds	60	17	23
27	D-A	never starts conversations	42	31	27
28	D-A	needs supervision outdoors	0	99	1
29	Ag	angry easily	41	32	27
30	D	drowsy during daytime	52	28	20
31	D-PD	needs help when dressing	21	36	43
32	D	incontinent at night	51	10	39
33	D	needs protection from falling out of bed	68	3	29
34	D	objectionable during the night	76	14	10
35	D	restless at night	78	14	8

Legend: D = Dependency, Ag = Aggressiveness; PD = Physical Disability, De = Depression, OC = Orientation & Communication, A = Apathy

Factor analysis

Table 2 shows the loadings of the 35 items on the 4 factors (I-IV) in the original analysis (O) and the present analysis (P). For example, item 1 had a loading of 0.32 on factor 1 in the original study (O-1), and a loading of 0.22 on factor 1 in the present study (P-1). The loading of an item on a factor is an indication for the correlation the item has with that factor. The items forfilling the requirements to be included in a

certain scale, are printed in bold. The percentage of explained variance was 42% in the original study: 24%, 7%, 7% and 4% for each of the four factors respectively. In the present study this variance was 41% (see Table 2). The results for the different factors will be explained, as well as the implications they have for the different subscales. Table 3 shows the number of items entered into the different subscales in each of the studies.

Scale 1: Dependency (O-I, P-I). Eighteen items had a loading higher than 0.45 and would have been entered into the subscale. Items 6, 9 and 15 were not included in the original scale, the other 15 were. The loadings of the items 9 and 15 differed significantly from the original factor loadings (0.21 against 0.61 and 0.39 against 0.61 resp.). The original scale Dependency contained eight items which would not have been entered in the subscale in our study because of the low loadings; the loadings varied from 0.06 to 0.41. The biggest differences on the level of items occurred with item 9 ("needs help when walking"), 13 ("doesn't know any of personnel by name") and item 21 ("urinates and defecates at the wrong place").

Scale 2: Aggressiveness (O-II, P-II). Both analyses showed great similarity. All 5 items had a loading of at least 0.30 in both analyses. In the present analysis item 8 ("sad") and 23 ("unwilling to do things asked of him") would also have been included in this scale. In the original analysis they had loadings of 0.26 and 0.01 respectively.

Scale 3A: Physical Independence (O-III, P-IV). Factor 3 of the original analysis has to be compared with factor 4 of our study. Of the original three items only item 3 would have been included, because of the low loading values of item 6 ("needs protection from falling out of chair") and 31 ("needs help when dressing"), -0.19 and 0.09 respectively.

Scale 3B: Depression (O-III, P-IV). In our analysis the 3 corresponding items had loadings of no more than -0.12 (item 8), -0.23 (item 16) and -0.03 (item 19).

Scale 3C: Orientation & Communication (O-III, P-IV). Of the four original items two came back. Item 11 ("unable to find his way around the ward") and 17 ("doesn't respond to his name") had loadings of only 0.23 and 0.19. In our study we could include item 10 ("does not make himself understood"), which could not be included in the original study (had a loading of 0.29).

Table 2. Factor loadings on the 4 factors I-IV, in the original (O) and in the present (P) analysis

Item	description	O-I	P-I	O-II	P-II	O-III	P-IV	O-IV	P-III
1	threatens verbally to harm others	32	22	65	72	03	04	05	11
2	accuses others of harming him	17	-02	63	68	11	-03	-02	13
3	needs help when eating	67	75	-23	-06	20	09	10	-06
4	incontinent during the day	71	61	-28	-03	13	-05	21	-17
5	hits and kicks other patients	40	36	46	54	-03	05	14	11
6	needs protection from falling out of chair	40	49	-16	-11	41	-19	20	-16
7	objectionable during the day	32	16	51	57	08	08	24	18
8	sad	16	17	26	41	46	-12	-08	12
9	needs help when walking	21	61	-21	-12	70	-44	-06	-20
10	does not make himself understood	68	64	-22	-15	-29	49	09	-02
11	unable to find his way around the ward	76	53	-18	-07	-11	23	07	01
12	doesn't know in which institution he is	64	38	-06	-15	-44	30	-12	05
13	doesn't know any of personnel by name	63	17	-05	-15	-39	18	-15	04
14	doesn't understand others	69	55	-16	00	-33	46	14	03
15	doesn't help out on ward	39	61	-10	-15	26	-10	-32	01
16	utters physical complaints	-11	24	21	05	57	-23	-06	-01
17	doesn't respond to his name	50	47	-15	-01	-30	19	14	-09
18	occupied in useless activity	65	67	-01	-10	-09	-13	-36	01
19	weeps easily	17	20	17	22	46	-03	00	08
20	doesn't socialize with other patients	61	65	-02	-11	22	-21	-37	-11
21	urinates and defecates at the wrong place	63	24	02	17	-01	24	23	07
22	doesn't help other patients	50	68	-10	-10	10	-10	-39	-02
23	unwilling to do things asked of him	59	51	01	31	-08	06	-23	02
24	no privileges to leave the ward	36	31	-11	-09	13	-24	-42	-02
25	engages in useless repetitive activity	53	32	10	21	-16	28	20	12
26	makes repetitive vocal sounds	49	41	23	20	05	15	19	23
27	never starts conversations	61	57	-07	-21	-24	-23	-35	-13
28	needs supervision outdoors	50	06	-09	-03	16	-07	-37	-04
29	angry easily	21	27	58	74	14	-01	06	13
30	drowsy during daytime	53	57	05	-14	21	-17	-12	-12
31	needs help when dressing	59	75	-27	-11	36	09	-06	-01
32	incontinent at night	72	65	-27	-04	12	-03	13	-14
33	needs protection from falling out of bed	49	63	-11	-12	26	-23	19	-17
34	objectionable during the night	47	27	29	07	08	-02	28	89
35	restless at night	52	28	24	08	18	-05	28	83
explained variance in %		24	23.1	7	8.3	4	4.2	7	5.4

In this table the factor loadings are written without the decimal-point; i.e. 32 = 0.32

Scale 4: Apathy (O-IV, P-III). In fact factor 4 of the original study should be compatible with factor 3 of our study. The outcome was however totally different. The Apathy items in our study gave a totally different picture. Only items 34 ("objectionable during the night") and 35 ("restless at night") were scoring extremely high. A proper name for scale 4 of our study could be "Nightly Behaviour". Because of these differences in results, we decided to do an additional factor analysis, excluding items 34 and 35. This analysis had as a result that, except for minor differences in the other factors, the scale Apathy showed itself more or less. Of the seven items three had a loading higher than 0.30 (items 18, 20 and 27), three had a loading of 0.12, 0.27, and 0.17 and item 28 had an insignificant factor loading of -0.04.

Table 3. Congruence between the original (O) and the present (P) analysis in the number of items incorporated (+) or not (-) into the 4 factors.

Scale	Factor		Number of items	O+P+	O+P-	O-P+	O-P-
Dependency (D)	O-I	P-I	23	15	8	3	9
Aggressiveness (Ag)	O-II	P-II	5	5	0	2	28
Physical Disability (PD)	O-III	P-IV	3	1	2	0	32
Depression (De)	O-III	P-IV	3	0	3	0	32
Orientation & Communication (OC)	O-III	P-IV	4	2	2	1	30
Apathy (A)	O-IV	P-III	7	0	7	2	26

Discussion

The scales Dependency, Aggressiveness and Orientation & Communication were more or less in congruence with the original analysis. However, the scales Depression and Physical Disability were almost totally unrecognizable. Instead, a new scale (Nightly Behaviour) could be created.

The scale Apathy was only recognizable when the items "restless at night" and "objectionable during the night" were not used in the analysis. The mean scores of the first mentioned three scales were significantly higher than the means in the original analysis. In our opinion this is a result of difference in the population used in both analyses. These scales are exactly the ones which show the main differences in somatic and psychogeriatric patients. In the case of Orientation & Communication the higher results are rather obvious, because bad orientation and communication is one of the reasons for admitting a patient to a psychogeriatric Dutch Nursing Home. Regarding the Dependency, it looks as if the differences between the two analyses are mainly caused by items concerning mental impairment. It concerns not only items from Orientation & Communication, but also items like the numbers 10, 11, 21,

25 and 26. If we subtract the sum of all the items concerning mental impairment (10 to 14, 17, 21, 25 en 26) from the score for Dependency, it can be seen that the difference in means from the present and original analysis is only 1.7 (11.3-9.6), instead of 6.7 (19.9-13.2) without subtraction.
The higher mean scores for Aggressiveness could match with a change or an increase in premorbid characteristics, loss of decorum, and (sexual) misbehaviour which can occur in the course of dementia, but could also be caused by the problems the patients have in getting acquainted with the new environment and with the (many) new tenants. The factor Nightly Behaviour indicates in fact only that most of the psychogeriatric population shows this kind of behaviour.
In our study the subscale Depression as such was unrecognizable. The item "sad" fell into the subscale Aggressiveness and "weeps easily" scored a loading of 0.22 on that factor. Apparently there is no clear-cut pattern of depressive behaviour often found in somatic Dutch Nursing Homes, where patients show depressive behaviour because of their physical disability, which in return can cause new physical complaints (see also [1], page 16).
In our analysis we found correlations of 0.09 and 0.16 respectively between "utters physical complaints" on the one hand and "sad" and "weeps easily" on the other hand. In the original study these figures were 0.40 and 0.35. The subscales Apathy and Physical Disability were hardly recognizable. In the original analysis all items except items 24 and 28 had enough loading on factor P-I to be entered into the scale of Dependency.
Besides differences in study population, there are probably other factors which can cause differences in the factor structure:
1. The original study used 42 items, and we used the 35 items of the BOP-scale. Probably this has only a minor influence, because the loadings of the 7 missing items on the four factors in the original study were so little that they were excluded anyway. The exact influence which these items might have had on the psychogeriatric population is not known to us, because we had no data about these items. A considerable influence would have been more likely if items with a high loading on one the four factors would have been excluded from the analyses, such as we described in our analyses without the items 34 and 35;
2. in the original study patients had to be institutionalized for at least one month; in our study the BOP's scored in the observation period were used as base for the analysis. It is not clear what influences this difference had on the factor structure;
3. in the original study patients who were totally bedridden were not included in the analysis; in our study this was not a condition;

4. in the original study patients had to be more than 60 years old, in our analysis this was no criterion; nevertheless very few patients were under the age of sixty.
In the original analysis 42% of all variance was explained by the four factors. In our analysis this was 41%. The differences were much more pronounced between the groups than within the groups, although the different behavioural patterns in psychogeriatric patients were pronounced enough to be described by a factor. It is intrinsic to a factor analysis that re-analysis on a subpopulation gives a different factor structure [9]. It could be interesting to investigate the stability of the structure for different subgroups (for instance gender, degree of dementia). The item response model [10] would probably be more suitable for dealing with such problems. In principle it would have been possible to take more factors into account. However, a comparison with the original study would have been impossible then, because the procedure would have been different. Moreover, in our analysis the fifth factor showed a variance less than 1 percent, which percentage is usually used as the lower limit [11].
We do not directly advise to develop another scale especially for psychogeriatric patients than the widely spread BOP rating scale, although a study of the applicability of a similar scale such as the GIP is recommended [12, 13], especially when both the BOP and the other scale are being used. Another reason not to put the BOP rating scale aside could be that more and more Dutch Nursing Homes have wards for somatic and for psychogeriatric patients. When a patient is internally replaced to another ward, a common scale is of utmost practical importance. In the psychogeriatric setting more attention could be paid to the special factors which emerged from this study, such as nightly behaviour. In that case it is recommended to describe specific behavioural aspects of a specific patient with the help of one or more of the fourteen subscales of the GIP [13]. Last but not least we advise to use the forms of the BOP or any other rating scale not only as a tool for patient observation, but also for the applications already mentioned in the introduction.

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Appendix. Part 2. Fall incidents in a psychogeriatric Dutch Nursing Home.

Since the early eighties many Dutch Nursing Homes have founded an advisory committee for registration of Mistakes, Accidents, and Near Accidents (in Dutch FONA: Fouten, Ongevallen en Near Accidents), a committee already existing in hospitals. Nowadays this committee is also called Registration Committee for Incidents in Patient Care (Meldingscommissie Incidenten Patiëntenzorg). This committee has a multidisciplinary quality control function, and is especially concerned with incidents in an institution. Most Dutch Nursing Homes adapted the FONA-model of the hospitals to their own situation. The type of incidents is usually less complex than in hospitals, and in most cases a certain pattern can be recognized [1].
Especially during the last years there is an increasing interest in fall incidents in foreign literature. Most research however is focused on incidents at home or in a hospital. In the Netherlands there are only few publications about incidents and their registration in health care institutions, which pay attention to risk factors for falling [2-7]. There are also only few publications (from the United States), which deal specifically with fall incidents in patient with dementia [8-11].
In the psychogeriatric Dutch Nursing Home Stadzicht in Rotterdam exists a registration committee for Incidents in Patient Care since the end of 1987. During the study period, the committee consisted of seven members, excluding the researcher: a Dutch Nursing Home physician, three orderlies, a pharmacists assistant, an ergotherapist, and an occupational therapist. The committee had the duty to collect, register, and analyze the information about the incidents, obtained by registration forms, and to give free advice to the directory board about possible preventive measurements.
In this article the occurrence of fall incidents in a psychogeriatric Dutch Nursing Home will be pursued. In short we will describe which activities were undertaken as a result of the research up to this date.

Methods

Patients

The Dutch Nursing Home Stadzicht has a capacity of 261 beds. There are eight nursing wards, one admission/observation ward, and a day care ward. Transfer from the observation ward to a nursing ward or discharge happens after at least six weeks, but can extend to several months. Each ward has 25 to 30 patients, and between the

wards there is no difference with respect to mildly, moderately, and severely demented patients. The personnel on each ward consists of two teams, and each member of a team is responsible for the total care of a patient. The lay-out of the wards is identical.
From the period of investigation (January 1st, 1988 to January, 1st 1990) 409 patients passed through Stadzicht. The mean age on January, 1st 1989 was just above 82 years; 12% of the patients were men, and 88% were women. Their length of stay varied from a few weeks to several years. In most cases the reason of admission was Senile Dementia of the Alzheimer Type and multi-infarct dementia.

Registration forms
The analysis concerns registration forms collected in 1988 and 1989. For this purpose to each patient an identity number was assigned. In order to keep the analysis anonymous this number was noted on the registration form, and only this number was entered into the computer. The form consisted of 15 open questions, of which the answers were coded by the registration committee. The questions concerned name, gender, and ward of the patient; place, date, time, description, and possible causes of the incident; the health state of the patient before and after the incident; steps undertaken by the reporter; possible prevention in the future, injury or pain sustained by the reporter, and whether the family was informed. If the call was not anonymous, name and function of the reporter were mentioned. Reporting of incidents was not obligatory, and no sanctions were imposed on the personnel for not reporting the incident. If the reporter of the incident was a member of the family, the form was completed together with the personnel.
In this paper the risk factors gender, time, place and cause of fall incidents will be discussed. The consequences of the incidents and the preventive measurements will be described. Fall incidents were divided in two types: (observed) falls and found-on-ground incidents. An incident was coded as a fall if the patient was seen or heard at the moment of falling. If the patient was found sitting or laying on the ground, the incident was coded as found-on-ground-incident (fog-incident): the reporter could not be sure whether it was a real fall incident. The fall-frequency (FFY) per 1000 beds per year is calculated as the number of fall incidents per year times 1000 divided by the number of beds [7].

Results

General

During the observation period 2880 incidents were reported, 1345 in 1988 and 1531 in 1989. Four reports remained without date. Of the 409 patients who resided (for the whole or part of the period) in the Dutch Nursing Home, 52 (13%) had had no incident, 65 (16%) had one incident, and 292 (71%) had two or more incidents. The sort of incidents most occurring were fall and found-on-ground incidents: they accounted for 40% (1149 incidents) and 29% (831 incidents) of all incidents. Other sorts of incidents were eating non-edible products and diabetics eating food not allowed for them (9%), and mistakes in medicine delivery.

Fall and found-on ground incidents

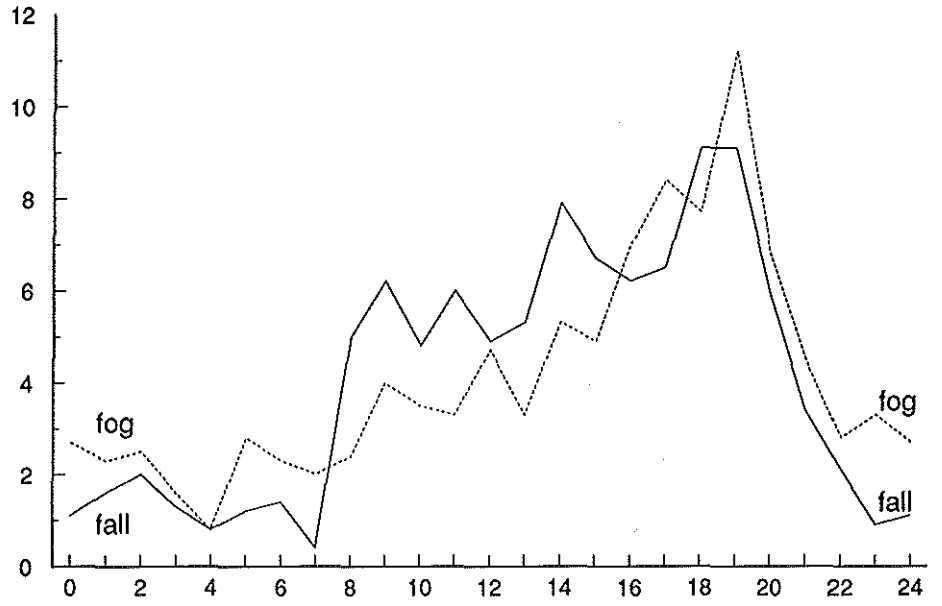
The 1149 fall incidents are equivalent with a fall frequency of 2201 per 1000 beds per year, whereas the 831 found-on-ground incidents are equivalent with 1591 per 1000 beds per year. On average a patient fell two times a year and was found on the ground 1.5 times a year. Men were responsible for 22% of the fall and 25% of the found-on-ground incidents (see Table 1). During the study period the prevalence ratio men/women was more or less constant: 88%:12% = 7:1. Nevertheless women were only 3.5 times more involved in fall and found-on-ground incidents. This clearly suggest that the risk of having such an incident for men is much higher than the risk for women.

Table 1. The number of residents, fall incidents, and found-on-ground incidents in a psychogeriatric Dutch Nursing Home, by gender.

	residents		fall incidents		found-on-ground incidents		all incidents	
Men	51	(12%)	250	(22%)	210	(25%)	655	(23%)
Women	358	(88%)	895	(78%)	619	(75%)	2225	(77%)
Total	409	(100%)	1145	(100%)	829	(100%)	2880	(100%)

Regarding the time of the incident, a day and night level can be distinguished: 87% of the fall and 77% of the found-on-ground incidents took place between 7 a.m. and 9 p.m (Figure 1). During the day the number of fall and found-on-ground incidents gradually increased.

Figure 1. The number of fall and found-on-ground (fog) incidents per hour by time of the day



The place of occurrence was usually the living room (35% of the fall, and 36% of the found-on-ground incidents), the hall way (32% and 27% respectively), and the bedroom (24% and 16% respectively). In 4% of the fall or found-on-ground incidents the toilet was the scene of the incident.

In 74% of the incidents the reporter has not mentioned a change in condition of the patient in the week previous to the fall. Only in 16% a change was noticed beforehand (e.g. a change in medication, drowsiness, increased confusion, agitation).

According to the reporter 45% of the fall and 38% of the found-on-ground incidents had an intrinsic cause (Table 2). Intrinsic factors mostly concerned mobility problems like 'balance and gait disturbances' and 'urge to walk while not be able to walk'. Extrinsic factors (environmental characteristics mostly concerned 'material, slipping,

stumbling', inattention of personnel, and behaviour of other patients, and was mentioned by the reporter as a cause in 26% of the fall and in 21% of the found-on-ground incidents.

Table 2. The number of fall incidents, and found-on-ground incidents by possible causes. More than one cause can be mentioned per incident.

	fall incidents		found-on-ground incidents	
	N = 1145	(100%)	N = 829	(100%)
Intrinsic causes				
Balance/gait disturbances	213	(19%)	119	(14%)
Sitting down wrongly	125	(11%)	71	(9%)
Wanting to walk while not able to	68	(6%)	51	(6%)
Fatigue	48	(4%)	40	(5%)
Agitation/confusion/irritation	55	(5%)	35	(4%)
Extrinsic causes				
Caused by other patient	53	(5%)	21	(3%)
Materials/stumbling/sliding/obstacles	213	(19%)	137	(17%)
Inattention/forgetfulness/mistake personnel	25	(2%)	7	(1%)
Other	204	(18%)	130	(16%)
Unknown	202	(18%)	246	(30%)
	1206	(105%)	857	(103%)

The consequences were usually temporary. According to the reporter no apparent harm occurred in 52% of the fall and in 65% of the found-on-ground incidents. In 30% and 25% of the incidents it caused fear, sadness and/or anger, and in 38% and 28% the incidents caused physical damage. Serious injuries occurred 41 times; 28 times it was a hip fracture (Table 3). Three of these fractures concerned male patients, and 25 of them female patients; this means that in men 0.6% (3 / 460) of the fall and found-on-ground incidents resulted in hip fractures; for women this was 1.7% (25 / 460).

Table 3. The number of fractures by type of incident.

	fall incidents	found-on-ground incidents	other incidents	total
Wrist fracture	3	2	2	7
Hip fracture	20	8	0	28
Other fracture	6	2	3	11
Total	29	12	5	46

According to the reporter 32% of the fall and 26% of the found-on-ground incidents could have been prevented. For this purpose several preventive suggestions were mentioned (Table 4). 579 Reports of the fall and found-on-ground incidents resulted in 597 suggestions. In many cases the suggestions were focussed upon safety precautions such as physical restraints and bedevils.

Table 4. Suggested preventive measures for fall and found-on-ground incidents

Suggestions	Fall incidents		Found-on-ground incidents	
Physical restraints	94	(25%)	73	(33%)
Bed fences	23	(6%)	24	(11%)
Pay more attention	29	(8%)	11	(5%)
More personnel	16	(4%)	7	(3%)
Doing job with 2 instead of 1	6	(2%)	0	(0%)
Being more careful when giving medication	2	(1%)	0	(0%)
Others	208	(55%)	104	(47%)
Total	378	(100%)	219	(100%)

Discussion

Registration of incidents in a two-year period resulted in 2880 incidents reports, of which 1980 (69%) were related to falls. This did not essentially differ from other figures in Dutch literature. According to Hoogwegt [12], who states that the number of incidents per year in a psychogeriatric Dutch Nursing Home is five times the number of beds, Stadzicht can expect 1300 incidents. The number of incidents we found was slightly higher. The success of the registration forms very much depends on the willingness of the personnel to register every incident. Therefore it must be expected that the number of incidents is higher in reality. The fact that the number of reports in the second year was 200 higher than in the first year suggests that the will-

ingness to report increased during the time of investigation; it is also possible that there was a real increase in incidents during the second year. A structural underreporting is not very likely regarding the fact that all information about major incidents in the medical files was also reported on the registration forms.
The frequency of the fall and found-on-ground incidents was related to time, place on the ward, and gender. There was a clear day and night level with peaks during the afternoon and the evening. Falls took especially place in the living room, the hall, and the bedroom; this is in accordance with the literature [2,3,5]. As expected, most falls took place where patients were remaining most of their time, the living room. Hoogwegt also found that in psychogeriatric Dutch Nursing Homes men are more fall-prone than women [3]. The risk of a hip fracture after a fall however was higher for women.
It was also found that falls particularly took place in nursing wards for moderately demented patients, and that mobile patients fall more often than less mobile patients [2,3,5]. Dementia patients fall often when climbing in and out of their (wheel)chair, or when walking unaccompanied. Possible reasons are balance disturbance, fatigue, dizziness, and so on. Although we asked for possible causes for the incidents, questions about mobility and the severity of dependency were not specified on the registration form.
The intrinsic factors mentioned appeared to be more important than the extrinsic factors. The balance and gait disturbances were the main cause of falling; environmental factors should however not be underestimated. Most fall and found-on-ground incidents did not cause much serious damage. Nevertheless, 41 incidents caused a fracture: 10% of all patients were thus involved, and 7% had a hip fracture. Percentages regarding the proportion of incidents with serious consequences vary between 6% and 16%. In Stadzicht the amount of fractures and hip fractures per 1000 beds per year was 79 and 54 respectively.
The figures lead to the conclusion that a Dutch Nursing Home is not as safe as might be expected. An effective prevention of falls has to be focused upon fall-proneness and fall-opportunities. First, a decline in fall incidents can be reached by improving the environmental characteristics. Possibilities are constructing facilities, the use of physical restraints, and nursing-related measurements. Some recommendations have already been given by Hoogerwerf and Tideiksaar [6,13]. Simultaneously a pre-fall assessment should be made in every patient soon after admission. The registration form can be useful to achieve this. A new registration form has been developed, which pays special attention to fall incidents as a result of physical restraints, the severity of dependency, and the situation in which the incident took place. The

reports are being processed automatically in order to receive the 3-monthly overviews more quickly and to be able to make more specific analyses if necessary. It is to be expected that this will result in a more effective and more extensive use of the information on the reports, and consequently also to a decrease in the number of (serious) incidents.

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