



## UvA-DARE (Digital Academic Repository)

### Wachten op opname. Hantering van de wachtlijst voor verpleeghuisopname en de gevolgen voor personen met dementie en hun mantelzorgers

Meiland, F.J.M.

**Publication date**  
2002

[Link to publication](#)

#### **Citation for published version (APA):**

Meiland, F. J. M. (2002). *Wachten op opname. Hantering van de wachtlijst voor verpleeghuisopname en de gevolgen voor personen met dementie en hun mantelzorgers*. [Thesis, fully internal, Universiteit van Amsterdam].

#### **General rights**

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

#### **Disclaimer/Complaints regulations**

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.



**Burden of delayed psychogeriatric nursing home admission in  
patients and their informal caregivers**

F.J.M. Meiland, J.A.C. Danse, J. F. Wendte, L.J. Gunning-Schepers, N.S. Klazinga.

[Quality in Health Care 2001;10(4):218-23]

## **Abstract**

### **Objective:**

To assess the deleterious effects of waiting for admission to a nursing home on the state of health of patients and their informal caregivers, and on the burden of caring.

### **Design and participants:**

Prospective longitudinal study consisting of interviews with informal caregivers during the period on the waiting list and after nursing home admission of the patient to a nursing home. Analyses of patients' files on diagnosis, date of registration on the waiting list, and date of admission to a nursing home.

### **Setting:**

Ninety three patients registered on waiting lists for admission to a psychogeriatric nursing home in two regions of Amsterdam.

### **Main results:**

Seventy eight of the 93 patients were admitted to a nursing home. The burden on the caregivers declined after admission of the patient but depressive symptoms did not. After 6 months a subgroup of 19 caregivers whose relatives were still waiting to be admitted were interviewed. The health of these patients remained stable during this waiting period and only problems in activities of daily living increased. The burden on these 19 informal caregivers and their state of health remained stable during the waiting period.

### **Conclusions:**

A decline in the state of health and a rise in the burden on caregivers during the waiting period did not occur. However, a decrease in the burden and an improvement in mental health could have started earlier if patients had been admitted earlier.

## Introduction

In the Netherlands the length of the waiting lists for psychogeriatric nursing home care is a constant concern for health policy makers, professional healthcare workers, and patients and their families.<sup>1-5</sup> This concern focuses on the negative effects of waiting for admission. However, waiting lists may also have a positive effect because they give patients (and their families) time to prepare themselves for admission to a nursing home, or it may be reassuring to know that the patient is "under review" and that, if something happens to the informal caregiver, the patient is already registered for nursing home admission. Furthermore, waiting lists enable nursing homes to plan admissions properly. When waiting times become longer, the negative effects may outweigh the positive; costs are higher because of use of other healthcare facilities while waiting (e.g. inappropriate stay in hospital), or because informal caregivers are less able to combine informal care with their work.<sup>6-8</sup> Moreover, patients and their informal caregivers may experience negative health effects or feel increasingly burdened during the waiting period, and the benefits of nursing home admission in terms of better quality of care for the patient and decline in the burden on the caregiver may be postponed. The effects of waiting times on the health of patients and their caregivers are the main focus of this study.

In the Netherlands in 1996 82.5% of persons aged 75 and over lived independently, 12.7% lived in residential homes, and 4.8% lived in nursing homes.<sup>9</sup> People in residential homes have some disabilities and/or lack of social contacts, and/or feelings of being unsafe. They may use facilities of the residential home still have their own home. Nursing homes are intended mainly for older people who need help with complex care needs resulting from chronic physical and/or psychogeriatric problems (usually dementia).<sup>10</sup> There are different types of nursing homes: somatic nursing homes, psychogeriatric nursing homes or combined nursing homes (with different departments for patients with either physical or psychogeriatric problems). In the Netherlands there are no financial constraints on admission to nursing homes because all citizens are insured for this type of care. However, patients do need a formal referral for nursing home admission from a needs assessment committee. These committees are organised at a municipal level. Often the regional institutions for ambulatory mental health care are involved in referring patients to a psychogeriatric nursing home.

The demand for nursing home care exceeds the supply, so patients requiring admission to a nursing home have to be put on a waiting list. Formal norms for acceptable waiting periods have not yet been established, but the National Association for Nursing Home Care (NVVz) considers a waiting period of 8 weeks to be acceptable for non-acute patients.<sup>5</sup> A mean waiting period of 17.5 weeks in 1997 in the Netherlands<sup>4</sup> is widely perceived as problematic. However, the time spent waiting can only be judged if the consequences, both positive and negative, are measured. This paper examines the negative health-related consequences for patients and their informal caregivers of a longer waiting period or postponed nursing home admission. The questions discussed are:

- (1) Does admission to a nursing home have an effect on the health status of patients and their informal caregivers?
- (2) In the subgroup of patients waiting at least 6 months, is there a decline in the state of health of patients and in the perceived burden on informal caregivers and their state of health during the waiting period?

To answer these questions a longitudinal research design was adopted with four measurement points during the waiting period and two measurement points after admission of the patient to a nursing home. This study is part of a larger Waiting List Project into the management of the waiting list and the burden of waiting on patients and their informal caregivers.<sup>11</sup>

## **Methods**

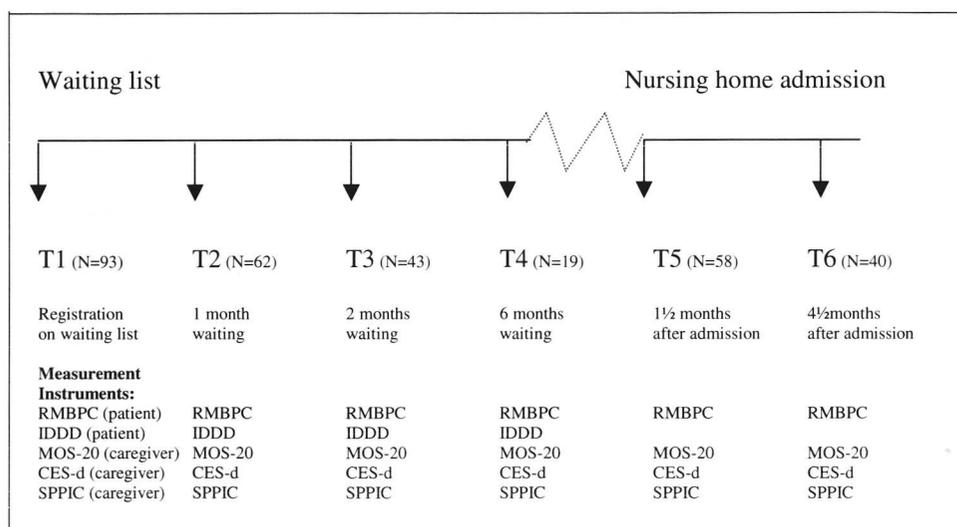
Ninety three informal caregivers of persons registered on the waiting list for admission to a nursing home were recruited from two out of five regional institutions for ambulatory mental health care (RIAGG) in Amsterdam. The researcher was seconded to the RIAGG during the data collection period to ensure that data stayed at the RIAGG until a signed informed consent was obtained. This informed consent procedure was adopted after consultation of the head of the Department of Health Law of the University of Amsterdam and approval by the RIAGG.

Data collection was from March 1997 to January 2000 and consisted of analysis of patient files at the RIAGG and follow-up interviews with informal caregivers. The methods have been reported in detail elsewhere.<sup>11</sup> Respondents could choose to have the interviews at their homes, in our department, or elsewhere, and were held without the patients being present. Besides structured questions in a face-to-face interview, the respondents completed four self-report questionnaires. The mean duration of the interviews was 94 min.

Analysis focused on two categories of changes during the waiting period: (1) change in the state of health of the patients over time; and (2) changes in the burden on the informal caregivers and their state of health. Measures within these categories will be described below. The Cronbach's alpha values presented here were calculated on the scores of the first interview (N=93).

An overview of the measurement points and the measurement instruments is presented in figure 1.

**Figure 1. Measurement points and measurement instruments during waiting period and after nursing home admission.**



### State of health of patients.

Information on the type of dementia and severity was gathered from the patient files at the RIAGG. Physicians of the RIAGG based the diagnosis on their own examination or, for example, on assessments in geriatric wards or memory clinics. The severity of dementia was categorised according to a scale used by the RIAGG and nursing homes in which the amount of psychogeriatric care needed determines the severity.<sup>12</sup>

The patient's behavioural problems and performance of self-care activities were assessed by the informal caregivers using two measurement instruments: (1) The Revised Memory and Behaviour Problems Checklist (RMBPC) which consists of 24 observable behavioural

problems in patients with dementia and contains three subscales - memory-related problems, depression, and disruptive behaviour (Cronbach's alpha 0.61, 0.77 and 0.63, respectively)<sup>13,14</sup>; (2) the Interview for Deterioration in Daily Living Activities in Dementia (IDDD) which consists of 11 questions on the frequency of required assistance in activities of daily living (Cronbach's alpha 0.81).<sup>15</sup>

### **Burden on informal caregivers and their state of health.**

The burden on caregivers was assessed using the Self-Perceived Pressure from Informal Care scale (SPPIC), which consists of nine items.<sup>16</sup> Respondents had to rate at on 5 point-scale whether they agreed with statements such as "the situation of my ... constantly demands my attention". Scores were dichotomised and total scores were calculated ranging from 0 to 9 (Cronbach's alpha 0.83).

Symptoms of depression in caregivers were assessed using the 20-item Center for Epidemiologic Studies Depression scale (CES-D)<sup>17</sup> which has been used frequently in studies of caregivers.<sup>18-20</sup> Respondents had to indicate on a 4-point scale (0-3) how often they experienced each symptom during the previous week. Scores ranged from 0-60, with higher scores reflecting more depressive symptoms. A standard cut-off point of 16+ may be used to classify patients at risk of developing clinical depression. Cronbach's alpha in our study was 0.92.

General state of health was assessed using the following five subscales of the MOS Short-Form Health Survey (SF-20).<sup>21 22</sup> : health perceptions (five items, Cronbach's alpha 0.82), physical functioning (six items, Cronbach's alpha 0.79), role functioning (two items, Cronbach's alpha 0.79), social functioning (one item), and mental health (five items, Cronbach's alpha 0.88). The subscale scores were transformed to 100 point scales, higher scores reflecting better functioning.

### **Analysis of data**

Descriptive analyses were performed on all relevant measures. Plots were made of the mean scores during the waiting period, and differences in mean scores between registration on the waiting list and after admission to a nursing home (T1-T5) were tested with paired *t* tests. These analyses were performed with SPSS 8.0. To examine changes during the waiting period (T1-T4) a standard repeated measures growth curve model was fitted to the data. The model assumes a linear trend over time with normally distributed random effects for both slope and intercept, as well as independent normally distributed measurement errors. Calculations were

carried out within the statistical analysis package S-PLUS 2000 using the S-PLUS mixed-effect procedure lme.<sup>23</sup> Missing records were removed from the analysis.

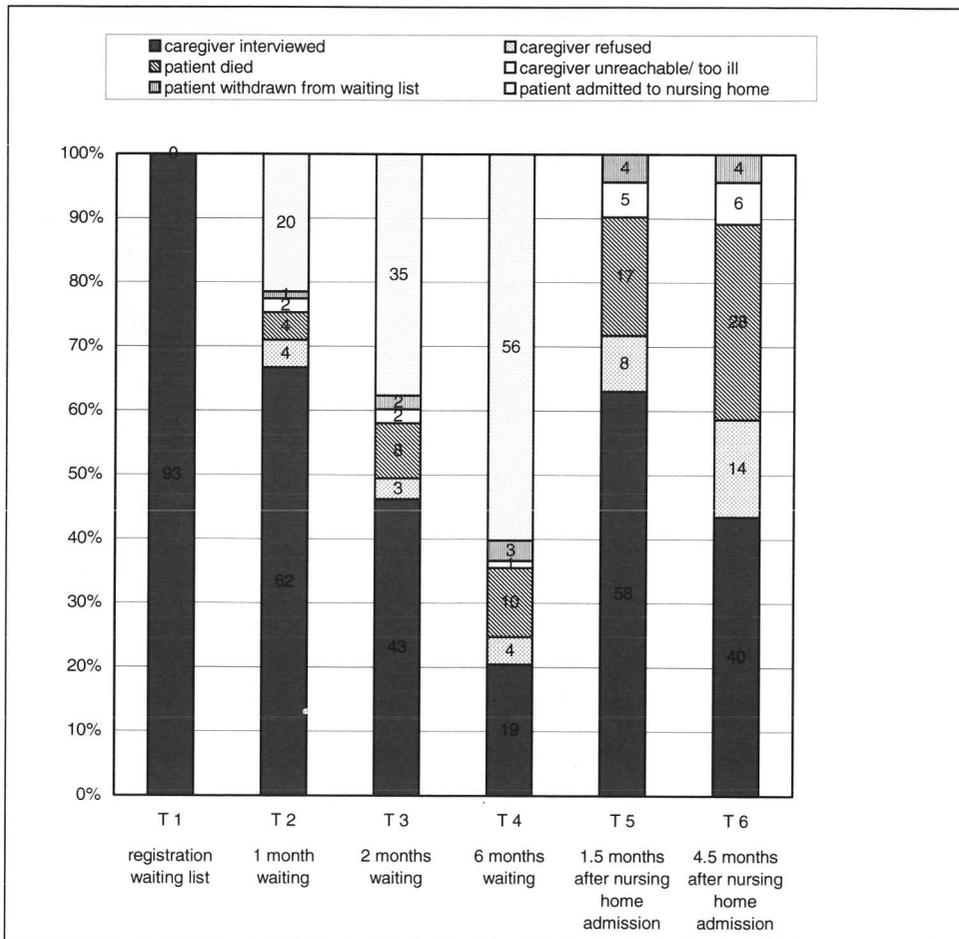
The level of significance was set at  $p < 0.01$  to account for multiple testing.

## Results

### Study sample

Information on the participants and drop outs during the follow up interviews is presented in figure 2.

Figure 2. Scheme of patients and drop-outs.



Note: At T2 4 persons died: 3 patients and one informal caregiver; at T3 the number of refusals was one less than at T2, because at T3 this respondent's relative died.

Ninety three caregivers were interviewed shortly after the patients was registered on the waiting list (T1). One month later (T2), 62 caregivers were interviewed; the remaining 31 were not interviewed at T2 because patients were admitted to a nursing home (n=20), one was withdrawn from the waiting list, four persons died, caregivers refused (n=4), could not be reached or were too ill (n=2). Nineteen caregivers were interviewed at all measurement points during the waiting period (up to 6 months (T4)), by that time, 11% had died (nine patients and one informal caregiver) and 60% had been admitted to a nursing home. Sixteen of the 19 respondents who waited at least 6 months were eventually admitted to a nursing home; of the remaining three, one was still waiting at closure of the data collection period, one had died, and one was withdrawn from the waiting list.

The characteristics of the 93 patients and their informal caregivers at T1 (registration on the waiting list) are shown in tables 1 and 2 respectively.

**Table 1 Characteristics of patients (N=93).**

Patients		
Mean age (sd)	83.2	(8.8)
Female, n (%)	70	(75.3)
Residence		
Alone	29	(31.2)
With spouse	15	(16.1)
With other people	7	(7.5)
In institution	42	(45.2)
Type of dementia		
Alzheimer's Disease	51	(54.8)
Vasculair Dementia	8	(8.6)
Other	34	(36.6)
Severity of dementia		
Mild	30	(32.3)
Moderate	56	(60.2)
Severe	6	(6.5)
Missing	1	(1.1)

**Table 2 Characteristics of informal caregivers (N=93).**

Informal caregivers		
Mean age (sd)	57.3	(12.3)
Female, n (%)	57	(61.3)
Relationship with patient, n (%)		
Spouse	16	(17.2)
Daughter	34	(36.6)
Son	20	(21.5)
Other family	21	(22.6)
Friend	2	(2.2)
Co-residency with patient, n (%)	22	(23.7)

### Changes in state of health and perceived burden between registration and admission

Table 3 shows differences in the state of health of patients and their informal caregivers for the 58 respondents who were interviewed at registration on the waiting list (T1) and 6 weeks after admission to the nursing home (T5).

**Table 3 Differences in health status and perceived burden between registration on the waiting list (T1) and admission in a nursing home (T5): results on paired t-tests.**

	T1		T5		N	t
	Mean	SD	Mean	SD		
<b>Patients</b>						
Memory problems (RMPBC)	20.90	4.81	18.90	6.25	51	2.56
Disruptive behaviour (RMBPC)	4.86	4.20	2.02	2.89	56	5.12 *
Depressive symptoms (RMBPC)	11.75	7.40	6.27	5.11	56	6.30 *
<b>Caregivers</b>						
Health perceptions (MOS-20)	65.64	20.97	65.36	23.07	55	0.11
Physical functioning (MOS-20)	68.48	28.81	60.91	32.43	55	1.95
Role functioning (MOS-20)	80.91	35.34	80.00	38.01	55	0.20
Social functioning (MOS-20)	87.92	20.13	84.15	22.99	53	1.14
Mental health (MOS-20)	65.67	21.54	69.09	20.36	55	-1.25
Perceived burden (SPPIC)	5.72	2.53	4.02	2.47	54	5.49 *
Depressive symptoms (CES-d)	12.63	9.00	10.96	9.63	54	1.50

\*  $p < 0.01$  Note: higher scores reflect more negative outcomes, except for MOS subscales where higher scores denote more positive outcomes.

Depressive symptoms and disruptive behaviour occurred significantly less frequently in patients after admission to the nursing home than at the time of registration on the waiting list. Three months after T5, paired *t* tests ( $n=33$ ) showed no significant difference between T5 and T6 on the RMBPC subscales.

With regard to changes in the burden on informal caregivers, the mean score on the SPPIC declined significantly after admission of the patient to a nursing home. This was the case for the total group of caregivers, for the subgroup who lived with the patients ( $t= 4.49$ ,  $df=12$ ,  $p=0.001$ ) and for the subgroup who did not live with the patient ( $t=4.00$ ,  $df= 40$ ,  $p<0.001$ ). However, for informal caregivers who cared for  $\leq 5$  hours a week there was only a trend in the decline in the burden ( $t=2.12$ ,  $df =15$ ,  $p=0.05$ ). No change was seen in depressive symptoms and general state of health of caregivers after admission of the patient to a nursing home compared with registration on the waiting list, nor was there any change in the percentage of caregivers who were at risk for developing depression (37% at T1 v 27.8% at T5; Chi-square= 2.37,  $df=1$ ,  $p=0.12$ ). Three months after T5 (that is, 4.5 months after admission to a nursing home) there were no changes between T5 and T6 in caregivers except for mental health which showed an improvement at T6 ( $t=-2.71$ ,  $df= 37$ ,  $p=0.01$ ).

### **Effect on state of health and burden on caregivers of long waiting period**

Nineteen patients were still on the waiting list 6 months after registration. In seven cases (37%) the informal caregivers lived with the patient and 74% of the informal caregivers were women. Table 4 presents mean scores on the questionnaires at each assessment during the waiting period for this subgroup of 19 patients.

The repeated measurement analysis used takes into account the dependency in measurements within an individual and differences between individuals at baseline measurement. Individual changes over time were analysed. The growth curve model assumes a linear trend. This model was fit using all available data given by patients who participated in all interviews during the waiting period ( $n=19$ ).

Evaluation consisted of testing the mean growth curve slope fit by the model. Only for activities of daily living problems was a significant increase found over time, given the assumed model ( $\beta=0.19$ ,  $df=56$ ,  $p < 0.0001$ ). Using the same growth model, there was marginal evidence of an increase in CES-d scores over time ( $\beta=0.12$ ,  $df=54$ ,  $p=0.03$ ). However, it must be kept in mind that this result occurs in the context of a repeat-testing (over 10 tests) on the same small dataset which may equally well explain this result.

No significant differences were found during the waiting period in the general health of caregivers (assessed by the five subscales of the MOS-20) and the perceived burden of caring on them.

**Table 4 Course in health status and perceived burden in long waiting patients and their informal caregivers (N=19).**

	T1		T2		T3		T4	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
<b>Patients</b>								
IDDD	33.11	(8.13)	34.42	(6.50)	36.79	(5.51)	38.26	(4.86)**
RMPBC- mem	20.53	(6.02)	19.89	(5.61)	19.06	(5.93)	20.26	(4.86)
RMBPC- dis	3.45	(3.31)	2.54	(4.31)	1.43	(2.81)	0.71	(2.17)
RMBPC- dep	8.26	(5.98)	5.30	(6.17)	3.27	(4.99)	1.09	(3.0)
<b>Caregivers</b>								
MOS- health perc	59.44	(16.62)	57.11	(17.66)	56.11	(19.44)	52.78	(22.83)
MOS- physical	54.63	(31.21)	42.59	(32.45)	50.00	(37.05)	44.74	(30.96)
MOS- role	75.00	(39.30)	65.79	(47.30)	47.22	(49.92)	68.42	(41.53)
MOS- social	77.76	(29.81)	74.74	(30.44)	65.88	(27.17)	73.68	(27.53)
MOS- mental health	59.56	(14.90)	58.74	(15.72)	57.33	(20.53)	53.89	(14.44)
SPPIC	6.06	(1.92)	6.06	(2.10)	5.44	(3.15)	6.58	(1.89)
CES-d	15.67	(8.36)	14.42	(9.76)	15.61	(10.28)	18.32	(8.75)*

**Note:** higher scores reflect more negative outcomes, except for MOS subscales where higher scores denote more positive outcomes.

T1= Admission on waiting list; T2= one month later; T3= two months later; T4= half a year on the waiting list.

IDDD = Interview for Deterioration in Daily living activities in Dementia;

RMBPC= Revised Memory and Behaviour Problem Checklist, with subscales "mem" = memory-related problems; "dis" = disruptive behaviour; and "dep" = depressive symptoms;

MOS= Medical Outcome Study – 20 item version, with subscales: health perceptions, physical health, role functioning, social functioning, and mental health;

SPPIC = Self-Perceived Pressure from Informal Care Scale;

CES-d = Center for Epidemiology Scale – depression.

\*\* change T1-T4  $p < 0.01$

\* change T1-T4  $p < 0.05$

## Discussion

The impact of nursing home admission on the state of health and the perceived burden on them was assessed first at six weeks after admission of the patient. At this time only the burden of caring declined compared with the time when patients were enrolled on the waiting list; general state of health and the level of depressive symptoms did not change. After a further 3 months most health status measurements and the perceived burden remained the same. Only the mental health of informal caregivers, assessed with a subscale of the MOS, improved. However, one aspect of mental health - that is, depressive symptoms - did not decline. The persistently raised levels of depression in caregivers after admission of the patients to a nursing home has been found in other.<sup>24,25</sup> Zarit and Whitlach<sup>24</sup> found that feelings of overload and tension decreased after admission of the patient to a nursing home, but high levels of anxiety and depression remained or increased. They stressed the difficulty of making the decision to institutionalise a relative. To assess improvements in health a longer follow up period might be needed.

The frequency of memory problems in patients as reported by informal caregivers showed no significant change after admission to a nursing home, but the occurrence of depressive symptoms and disruptive behaviour declined. Possible bias by taking proxies as informants on this subject may have influenced these results. Informal caregivers might have given socially desirable answers: they may have wanted patients to be functioning better in the nursing homes. However, we tried to address this problem by using questionnaires on patients' problematic behaviours and activities of daily living performance which assess observable behaviour.<sup>13,15</sup> The ratings of proxies appear to be more accurate when concrete and observable information was asked for.<sup>26</sup> Another explanation for better functioning of patients may be that they have fewer opportunities for disruptive behaviour such as acting dangerously or destroying property in the nursing homes; professionals in nursing homes are more experienced in coping and preventing disruptive behaviour of patients, doors are locked to prevent wandering, and dangerous items are not within easy reach.

Nineteen patients (20%) were still waiting to be admitted 6 months after registration on the waiting list. This waiting period is generally considered unacceptably long.<sup>5</sup> The most serious event to happen during the waiting time could be premature death. In our study 12% (10 patients and one informal caregiver) died during the waiting period. A survey among nursing

homes showed that the number of deaths during the waiting period increased to 39% in 1997.<sup>4</sup> The authors suggested a relation between longer waiting times and death rates. However, it is open to question whether nursing home admission could have prevented the deaths. In our study 10% died within 6 weeks of admission to the nursing home and another 12% of the total sample died in the following 3 months. Analysis on health status measurements in these patients who had been on the waiting list for more than 6 months showed that their memory problems, disruptive behaviour, and depressive symptoms remained stable. The performance of (instrumental) activities of daily living declined during the waiting period. This is consistent with reports in the literature: complex activities are impaired first and basic self-care activities are impaired later.<sup>27</sup>

Informal carers of patients with dementia are known to be burdened or to experience deleterious effects on their health.<sup>28-32</sup> Different models have been proposed in the literature to describe the course of mental health of caregivers over time. A longer duration of caring could lead to "wearing out" of caregivers in the "wear and tear model", and in the "adaptation model" the mental health of caregivers declines initially but is regained later on.<sup>33</sup> In the "trait model" caregivers show a stable pattern of mental health due to pre-existing coping skills.<sup>27</sup> The difficulty with the validation of these models is that information on the mental health of caregivers before they start giving care is often lacking. This is also the case in our study. Furthermore, patients were admitted to nursing homes during the waiting period which resulted in only a small sample of caregivers with a waiting period of 6 months. Although there was a trend towards increasing depressive symptoms, the general state of health and perceived burden of caregivers was generally fairly stable during the waiting period, which might support the adaptation model. A survivor effect may explain the fact that major health effects were not found, because the healthiest caregivers may have been the ones who continued to give care until 6 months after registration on the waiting list. The stable pattern of perceived burden and state of health should not be interpreted as an absence of serious problems—for example, the high levels of depressive symptoms in caregivers deserve further attention. In our sample mean depression scores are higher than in elderly persons in the community<sup>34</sup> or in a healthy sample of persons with comparable age.<sup>17</sup> High levels of depressive symptoms in caregivers are a consistent finding in the literature.<sup>18,20,31</sup> The finding in other studies that women are more depressed than men could not be replicated in this study. The general state of health of our sample was worse than in elderly people in the community for health perceptions and psychological health, but not for social functioning.<sup>22</sup> Informal

caregivers are considered to feel restricted in social activities, but this might not apply in our sample since most of the informal caregivers were not living with the patient.

In interpreting the results it should be pointed out that the number of patients with a long waiting times was small and that drop outs were inevitable because of admission to a nursing home. Biases may have occurred by recruiting respondents at the RIAGG; patients who were referred for nursing home admission while they were in hospital were underrepresented in this study, and patients who were admitted acutely could not be interviewed. However, this may not be a problem because the latter had not been waiting and patients in hospitals had not yet been admitted to the nursing homes but had received hospital care. The strength of our study was the longitudinal research design with multiple measurements of the state of health of patients and their caregivers, as well as the perceived burden of caring on the caregiver.

In conclusion, the deleterious effects on health of a long waiting period, on the one hand, and of delayed admission to a nursing home, on the other, were not unequivocal. Although patients died during the waiting period, even more died after nursing home admission. The problems in (instrumental) activities of daily living of patients increased during the waiting period, but the perceived burden and state of health of caregivers remained the same. On the basis of this study we conclude that negative effects of waiting may better be described in terms of undesirable postponement of improvement resulting from admission to a nursing home; patients showed less disruptive behaviour and fewer depressive symptoms. Furthermore, the perceived burden and, in the long term, the mental health of informal caregivers improved. A policy that encourages home care and aims to keep patients out of healthcare institutions for as long as possible should therefore be carefully scrutinised for deleterious effects on health.

## References

- 1 Government Committee on Choices in Health Care. Choices in Health Care. Ministry of Public Health, Welfare and Cultural Affairs, The Netherlands, 1992.
- 2 Nationale Raad voor de Volksgezondheid. Wachtlijsten. Advies van de Nationale Raad voor Volksgezondheid en het College van Ziekenhuisvoorzieningen [Waiting lists. Advice of the National Board on Public Health and the college of hospital services]. Zoetermeer, 1994.
- 3 Tweede kamer der Staten-Generaal. Financieel Overzicht Zorg, wachtlijsten in de zorg [Financial overview care, waiting list in care]. Tweede kamer, 1993-1994, 23 407, nrs. 1-2.

- 4 Gerritse AJ, Lorscheid JGG. De wachtlijstenquete bij verpleeghuizen 1998. [The waiting list survey among nursing homes 1998]. Utrecht: Nationaal Ziekenhuis Instituut, 1998.
- 5 Staatscourant [The Dutch Official Gazette]. Wachtlijsten voor verpleeghuisopname gegroeid [Waiting lists for nursing home admission increased]. Staatscourant 49, 1998.
- 6 Cantor MH. Family and the community: changing roles in an aging society. *The Gerontologist* 1991;31:337-346.
- 7 Brakman S. Adult daughter caregivers. *Hastings center report* 1994;24:26-28.
- 8 Smit RLC, Kroneman M. Wachtlijsten in de zorg [Waiting lists in care]. In: Post D, Stokx LPJ (ed). *Volksgezondheid Toekomst Verkenning 1997 deel VI: Zorgbehoefte en Zorggebruik*. RIVM, Bilthoven: Elsevier/De tijdstroom, Maarssen, 1997:119-35.
- 9 Sociaal en Cultureel Planbureau. Vraagverkenning wonen en zorg voor ouderen [Exploration of the demand for living and care for the elderly]. Rijswijk: SCP, 1997.
- 10 Schrijvers AJP, Duursma SA, de Weert-van Oene GH, et al. Care for the Elderly. In: Schrijvers AJP, ed. *Health and Health Care in the Netherlands*. Utrecht: De Tijdstroom, 1997: 101-9.
- 11 Meiland FJM, Danse JAC, Wendte JF, et al. Caregiver experiences of relatives of patients on the waiting list for admission to a psychogeriatric nursing home in the Netherlands. *Scand J Public Health* 2001;29:113-21.
- 12 Sipsma DH. Sociaal-geriatrische zorg en de geestelijk gestoorde bejaarde [Social-Geriatrics and the mentally disturbed aged]. *Nederl Tijdschr Gerontol* 1970;1:7-16.
- 13 Teri L, Truax P, Logsdon R, et al. Assessment of behavioral problems in dementia: the revised memory and behavior problem checklist. *Psychol Aging* 1992;4:622-31.
- 14 Teunisse S. *Clinimetrics in Dementia*. Enschede: PrintPartners Ipskamp,  
15 1997, 71-85.
- 16 Teunisse S, Derix MMA. The interview for deterioration in daily living activities in dementia: agreement between primary and secondary caregivers. *Int Psychogeriatr* 1997;9 suppl 1: 155-62.
- 17 Pot AM, Dyck R van, Deeg DJH. Ervaren druk door informele zorg: constructie van een schaal [Self-perceived pressure from informal care: construction of a scale]. *Tijdschr Gerontol Geriatr* 1995;26:214-9.
- 18 Bouma J, Ranchor AV, Sanderman R, et al. Het meten van symptomen van depressie met de CES-D [Assessment of symptoms of depression using the CES-D]. Groningen: Noordelijk Centrum voor Gezondheidsvraagstukken, 1995.
- 19 Schulz R, Williamson GM. A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychol Aging* 1991;6:569-78.
- 20 Alspaugh ME, Stephens MA, Townsend AL, et al. Longitudinal patterns of risk for depression in dementia caregivers: objective and subjective primary stress as predictors. *Psychol Aging* 1999;14:34-43.
- 21 Rose-Rego SK, Strauss ME, Smyth KA. Differences in the perceived well-being of wives and husbands caring for persons with Alzheimer's disease. *Gerontologist* 1998;38:224-30.
- 22 Stewart AL, Hays RD, Ware JE. The MOS Short-form General Health Survey. Reliability and validity in a patient population. *Med Care* 1988;26:724-35.
- 23 Kempen GIJM. Het meten van de gezondheidstoestand van ouderen; Een toepassing van een Nederlandse versie van de MOS-schaal [Assessment of health status among the elderly; an application of a Dutch version of the MOS-Survey]. *Tijdschr Gerontol Geriatr* 1992;23:132-40.

- 24 S-plus 2000. Professional release 2. Math. Soft. Inc. 1988-1999.
- 25 Zarit SH, Whitlatch CJ. Institutional placement: phases of transition. *Gerontologist* 1992;32:665-72.
- 26 Waltrowicz W, Ames D, McKenzie S, et al. Burden and stress on relatives (informal carers) of dementia sufferers in psychogeriatric nursing homes. *Aust J Ageing* 1996;15:115-7.
- 27 Sprangers MAG, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: a review. *J Clin Epidemiol* 1992;45:743-60.
- 28 Haley WE, Pardo KM. Relationship of severity of dementia to caregiving stressors. *Psychol Aging* 1989;4:389-92.
- 29 George LK, Gwyther LP. Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *Gerontologist* 1986;26:253-9.
- 30 Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist* 1986;26:260-6.
- 31 Wright LK, Clipp EC, George LK. Health consequences of caregiver stress. *Med Exerc Nutr Health* 1993;2:181-95.
- 32 Schulz R, O'Brien AT, Bookwala J, et al. Psychiatric and Physical Morbidity Effects of Dementia Caregiving: Prevalence, Correlates, and Causes. *Gerontologist* 1995;35: 771-91.
- 33 Dunkin JJ, Anderson-Haley C. Dementia caregiver burden. A review of the literature and guidelines for assessment and intervention. *Neurology* 1998;51:S53-S60.
- 34 Townsend A, Noelker L, Deimling G, et al. Longitudinal impact of interhousehold caregiving on adult children's mental health. *Psychol Aging* 1989;4:393-401.
- 35 Beekman ATF, Limbeek J van, Deeg DJH, et al. Een screeningsinstrument voor depressie bij ouderen in de algemene bevolking: de bruikbaarheid van de Center for Epiemiologic Studies Depression Scale (CES-d) [Screening for depression in the elderly in the community: using the Center for Epidemiologic Studies Depression Scale (CES-d) in the Netherlands]. *Tijdschr Gerontol Geriatr* 1994;25:95-103.