Care Dependency and Survival Among Female Patients with Alzheimer’s Disease: A Two-Year Follow-Up
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**Aim.** To investigate the relationship between the severity of the patient’s care dependency on the one hand, and the causes of death, co-morbidity, and survival on the other, and to find out which of these factors might be longitudinal predictors of survival.

**Methods.** A two-year follow-up study started in 1994 in the Netherlands. Subjects were 130 female nursing-home patients with Alzheimer’s disease (91 severely dependent, and 39 mildly dependent). Features analyzed in 1994 included the scale of care dependency, demographic data, and clinical information.

**Results.** In 1994, both subsamples differed significantly with respect to the duration of Alzheimer’s disease, duration of stay, and all nursing-care dependency features, but they did not differ significantly in age, age of disease onset, and co-morbidity. In both groups, the main causes of death were cachexia and/or dehydration. Survival prognosis varied with the level of care dependency. Compared to mildly dependent patients, patients with severe dependency had a 20% higher mortality than expected for the general population of the same age. Marital status, education, cardiovascular disease, and four care dependency features: body posture, day/night pattern, communication, and contact with others, are factors that significantly predict survival.

**Conclusion.** Survival prognosis of patients with Alzheimer’s disease varies with the level of care dependency.

**Key words:** Alzheimer’s disease; nursing care; nursing homes; survival analysis; the Netherlands

Nursing care in psychogeriatric nursing homes aims at patients with mental deteriorations, most of them with dementia (1). In the Netherlands, there are 70 nursing homes, with a total capacity of 25,600 inpatient beds in which psychogeriatric patients are admitted. These nursing homes provide long-term treatment which includes activities such as care, treatment, and therapy (1,2). In this study, a psychogeriatric nursing-home population was followed during a two-year period in order to investigate the relationship between patients’ survival and functioning. There are many reports describing the survival in relation to demographic factors and various kinds of functioning, such as social, economic, cognitive, physical, and clinical functioning (3,4). On the basis of these factors described in literature, Boersma et al (5) report that a shorter survival in dementia is associated with multi-infarct-dementia, dependency in daily living activities, somatic co-morbidity, incontinence, alcohol abuse, severity of dementia (“how far”), progression of cognitive deterioration (“how fast”), institutionalization, behavioral problems, and language disorders or aphasia. Although most of these studies generate knowledge for the medical and psychological disciplines, prognosis of survival among patients with dementia is also an important issue for nurses. During a patient’s stay at a nursing home, nurses are confronted with increasing care dependency and, ultimately, the patient’s death. Studies addressing the survival from a nursing perspective are sparse. According to Miller (6,7), literature on patient dependency shows that increasing dependency on nursing care is associated with higher mortality. Van Dijk et al (8) report that dependency factors in general have some prognostic value. However, it is questionable whether there is a relationship between patient dependency on nursing care and prognosis of survival, since care dependency does not represent the cause but the effect of health problems, and most causes of death are reflections of the course of somatic illness preceding death (5). Therefore, we formulated the research questions regarding the differences in demographic and care dependency characteristics between patients with severe and mild dependency, their co-morbidity and causes of death. We also took a special interest in the survival prognosis related to the severity of the patient’s care dependency and in the question which care dependency, demographic and/or clinical factors might be a longitudinal predictor of survival in the Alzheimer’s disease.
Patients and Methods
This research project has been designed as a panel study, which is a specific type of longitudinal studies. In the panel studies, the same subjects are used for obtaining data at two or more points in time (9).

Subjects
A panel for this study was sampled from a psychogeriatric nursing home in the northern part of the Netherlands that consented to participate in the research project. Since 1994, 130 female patients with a clinical diagnosis of Alzheimer’s disease from the nursing home population (N=219) were included in the study. The diagnosis of Alzheimer's disease was made on the basis of the Diagnostic and Statistical Manual of Mental Disorders (4th ed.) criteria for dementia (10). Patients with dementia due to other causes (N=73) and patients (N=5) who returned to their own home or were admitted in another long-term care facility during the research period were excluded from the study. Eleven male patients with Alzheimer’s disease were also excluded from the sample.

Instrumentation
Data were collected using two sources. The first was the Care Dependency Scale (CDS), which provides a framework for the care dependency status of institutionalized demented patients. The CDS measures 15 human needs: eating and drinking, incontinence, body posture, mobility, day/night pattern, getting dressed and undressed, body temperature, hygiene, avoidance of danger, communication, contact with others, sense of rules and values, daily activities, recreational activities, and learning ability. The possible score in each item ranges from 1 to 5; the higher the score, the less dependent patient is on care. The last question on the scale asks for a specific rating of the degree of care dependency on a 5-point Likert-scale ranging from 1 for completely dependent to 5 for almost independent of care. The CDS has been psychometrically tested in four studies. Content validity was established by 44 experts in a Delphi survey (11). Interrater reliability (k) was 0.40-0.64; test-retest reliability (k) was 0.55-0.80; and Cronbach’s Alpha was 0.97 (12). Construct validity was determined by a factor analysis and resulted in a one-factor solution (Eigenvalue 10.72). In addition, Mokken-scale analysis for the whole scale resulted in a high H-coefficient, 0.75 (13). In the fourth study, criterion-related validity was examined. Findings indicate adequate support for the criterion-related validity of the CDS (14).

The second source used in this study was the SIG Verpleeghuis Informatie Systeem (SIVIS), a national registration system of clinical, nursing, and demographic data of Dutch nursing-home patients (15).

Procedure
In order to investigate the survival prognosis, at the study entry the panel was divided into a group of patients with mild dependency and a group of patients with severe dependency. The difference in the severity of the patients’ care dependency was based on the median score of the CDS, which ranged from 0 to 75. The median score for the whole panel was 37.5. Patients with the score 37.5 or less were regarded as having severe care dependency, and the group with the score higher than 37.5 consisted of patients with mild care dependency.

Data collection (T1) started in April 1994 with 130 patients. They were followed until April 1996 or until death. CDS was assessed for all patients at T1 time point. The ratings were carried out by the nurses or nurse aides who were most involved in the daily care of the particular patient and who knew how to use the instrument. Filling in the CDS instruments took about 15 minutes. To ensure the patients’ privacy, the names of the participants were encoded. The measures of dependency on care used in this study were the 15 features and the sumscores of these 15 items.

Demographic data on age, marital status, education, and time of admission was obtained from the patient’s demographic record in the SIG Verpleeghuis Informatie Systeem at T1 time point. Clinical records of the 62 patients who died within the two-year period were examined for the date of death, age at death, and cause of death. Cause of death of 10 patients was obtained from autopsy records, whereas for the remaining 52 patients, the clinical records made by attending physicians were consulted. Supplementary clinical information on DSM-IV diagnoses and co-morbidity was found in retrospect in the patient’s medical care plan at T1 time point. Date of onset of the Alzheimer’s disease was obtained from the closest informant available at the time of admission. This information was registered in the patient’s medical care plan.

As the study aimed to investigate survival, the following study variables were chosen. The expected number of survivors was based on the mortality quotient derived from the 1995 Dutch life tables for the general population (16). The longevity quotient (LQ) was used as a dependent variable to predict survival. LQ was calculated according to Palmore (17), as the observed number of years of survival after the study entry, divided by the expected number of survival years after study entry. For those patients who were still alive at the study endpoint, an estimate was made of how many years they will
have lived since the study entry by adding the present number of years survived since the study entry
to the expected number of years now remaining according to the 1995 Dutch life tables for the
general population of the same sex and age (16).

Statistics
Data were analyzed using the Statistical Product and Service Solution Windows version 7.5. (18). The
frequencies procedure was used to provide statistics on mean and standard deviation. T-test for
independent samples was used to compare the means of item variables for both non-survivors and
survivors at the study entry. In order to examine variables explaining survival, a multiple regression
analysis was performed. In all analyses, only p-values of less than 0.05 were considered significant.

Results
At study entry, no significant differences were revealed between severely and mildly dependent
patients in their age, marital status, education, and age at the onset of the Alzheimer’s disease (Table
1). Severely dependent patients had a longer duration of the disease (p<0.001) and a longer duration
of stay at a nursing home (p=0.001) than mildly dependent patients. At study entry, 88% of the
patients had one or more somatic co-morbidities, and 12% had multi-pathology with more than three
somatic chronic illnesses. Table 1 shows co-morbidity in both subsamples related to the nine most
frequently occurring diagnostic categories. Co-morbidity mainly related to cardio-vascular diseases,
musculoskeletal problems, and cerebro-vascular diseases. Severely and mildly dependent patients
did not differ in any of the categories of the somatic co-morbidity. Finally, the CDS item scores for
both groups were compared (Table 1). T-tests for independent-samples confirmed that both
subsamples were different in each of the CDS features (p=0.001).

Table 1: Characteristics of female patients with Alzheimer’s disease (AD) at study entry, by severity of
care dependency and significance. [view this table]

Table 2: Underlying causes of death in Alzheimer’s disease (No., %). [view this table]

The leading primary underlying causes of death according to the dependency status among non-
survivors are shown in Table 2. Cachexia and dehydration predominated as causes of death (32%),
followed by pulmonary disorder (26%) and cardio-vascular disease (21%). It appears that pulmonary
disorder, as well as cachexia/dehydration, increase as causes of death with the increase in the
degree of care dependency.

On the basis of the 1995 mortality quotient for the general population (16), the expected number of
death persons was 10 in patients with severe dependency and 4 in the patient group with mild
dependency. After 2 years, the observed number of survivors in the group with severe dependency
was 43 (89% expected, 47% observed), and 26 in the group with mild dependency (90% expected,
67% observed). Although the expected survival percentage in the two dependency groups was almost
equal, a significantly higher percentage of the observed patients who survived was found among
patients with mild dependency.

There was a difference in the course of mortality between patients of the two care dependency groups
(Fig. 1). Compared to the mild dependency group, a more progressive course of mortality was found
in patients with severe dependency. More than 50% of the patients with severe care dependency died
within 2 years. In the first two quarters after the study entry, mildly dependent patients had even the
same survival prognosis as females of the same age in the general population. In this group, about
25% of the patients died within 2 years.

Figure 1: Course of mortality by care dependency status. Rhombs, expected mortality for the general
population; squares, observed mortality among severely dependent; triangles, expected
mortality for the general population; crosses, observed mortality among mildly dependent.
[view this figure]

Table 3: Significant predictors of longevity quotient at study entry: stepwise regression analysis. [view
this table]

To study whether care dependency, demographic and/or clinical factors were predictors of survival,
LQ was used as the dependent variable in a regression analysis, with the following independent
variables at study entry: age, marital status, education, age of onset, duration of Alzheimer’s disease,
duration of the stay at the nursing home, co-morbidity, the 15 CDS items, and the degree of care
dependency. The possible interaction effects between both dependent and independent variables
were entered in a stepwise procedure, with a criterion for entry set at the 0.05 level of significance. Only those variables were revealed that added a statistically significant increase to the variance explained. A separate regression analysis was performed for the total panel and for both dependency groups (Table 3). The first column of the Table 3 presents standardized b coefficients for each predictor, showing the relative influence of each predictor on longevity quotient when all the others are considered simultaneously (18). The second column presents the adjusted R2, which is designed to compensate for optimistic bias and which can be seen as the proportion of the total variance on the longevity quotient accounted for by each independent variable (17). In the total panel, the CDS item “body posture” was the strongest predictor for survival; it accounted for 7.4% of the total variation. Although their contribution was low, effects of cardiovascular disease, day/night pattern, education, and marital status accounted for 5.4%, 3.7%, 2.0%, and 2.8% of the variance, respectively. In the severely dependent patient group, longevity quotient was predicted independently by cardiovascular disease (3.4%), body posture (4.4%), and contact with others (3.2%). In the mildly dependent group, the regression procedure showed significant effects of communication and marital status, which accounted for 16.5% and 8.8% of the variance, respectively.

Discussion
Comparing patients with severe dependency and those who were assessed as mildly dependent, descriptive findings showed that the first group had a longer duration of Alzheimer’s disease at the study entry, stayed longer at the nursing home, and were more dependent on care. These findings are well in accordance with the practical experience of (nurse) professionals. The mean age at onset among the total panel (75.9 years) was in accordance with other studies (19-21) and the mean duration of Alzheimer’s disease (8.5 years) was higher when compared to studies by Diesfeldt et al (19) and Koopmans et al (20).

The presence of cardiovascular diseases as co-morbid condition was found for 36.1% of those in the total panel who deceased. The similar percentage was reported by Koopmans et al (20). Regarding co-morbidity, the limitation of our study was that only the measures taken at the study entry were used for analysis and that new co-morbid factors between study entry and study endpoint were not considered. The leading reported cause of death was cachexia/dehydration, followed by pulmonary disorder and cardiovascular disease. These findings are similar to the studies by Koopmans et al (20), Olichney et al (22), and, recently, Boersma et al (5). It is very interesting that in cases of cachexia and dehydration no other pathology was reported in the death certificate. This suggests that these symptoms are directly caused by the general weakness of the Alzheimer’s disease patient in the terminal state. If renal insufficiency was reported, it was the result of dehydration because of the negative fluid balance, i.e., very low intake of fluid as the result of the patient’s mental state. General policy at Dutch nursing homes is to give no parenteral fluid when the Alzheimer’s disease patient is in a terminal state. Malignancy was rarely reported as the cause of death, whereas it was the second leading cause of death (accounting for 25% of the 1995 deaths of persons 65 years of age and older) for a comparable age group in the Dutch population (17). Olichney et al (22) reported the same phenomenon in their study and pointed to two possible explanations: dementing patients have a markedly increased mortality rate attributable to a variety of causes other than neoplasms, and there could be a potential selection bias. Regarding survival prognosis in both dependency groups, the observed mortality rate was lower than it was expected. The results demonstrate a clear difference of 20% in excess mortality between severely dependent patients and mildly dependent patients. The excess mortality seemed to be most prominent in the second year of study. Regarding the non-survivors from the mild dependency group, these patients were probably severely demented and had a more progressive mortality course. This is in accordance with the general idea of the existence of Alzheimer’s disease-subtypes and variability in the course of dementia (5,23). Regarding care dependency, all the patients did not successively attend the several stages of care dependency. In accordance with other studies (8), another general conclusion from this study can be that patients with Alzheimer’s disease, compared to the general population, have considerably shorter survival rates.

Regression analysis revealed demographic, socio-economic, medical, and nursing factors that could predict the survival of Alzheimer’s disease patients. In the total panel, the CDS item “body posture” was the strongest predictor of longevity. This variable assessed the extent to which the patient was able to adopt a position appropriate to a certain activity. The significance of this phenomenon is comparable with cachexia and dehydration, because it is the expression of pathological and psychophysiological functioning caused by the progression of cortical and subcortical neuronal decay. Patient with a high score on this item is chairbound or even bedridden, which can easily lead to several physical complications like bronchopneumonia, bedsores, and urinary incontinence. Cardio-
vascular disease was the second significant predictor of survival. The third variable that entered the regression analysis was “day/night pattern” suggesting that a normal day/night pattern and enough rest may contribute to longevity. The correlation between “day/night pattern” and longevity can be explained in the similar way like “body posture” factor. The finding that education predicted longevity reflects the importance of the level of education of institutionalized patients because poorer education puts patients at a greater risk of earlier death. The demographic variable “marital status” was the final predictor in the total panel, indicating that being single had a significant negative effect on survival. Longevity in patients with a severe dependency status was predicted independently by cardiovascular disease, body posture, and contact with others. These variables accounted for 11% of the total variance. Thus, being severely dependent on (nursing) care, having a cardiovascular disease, inability to adopt a position appropriately for a certain activity, as well as inability to appropriately make, maintain, and end social contacts put Alzheimer’s disease patients at high risk of death. Longevity in the mildly dependent patient group was predicted first by communication and second by marital status. The communication item is strongly related to the nursing diagnosis “Impaired verbal communication” with Alzheimer’s disease as a common cause (24,25). Apparently, having language disorders or aphasia puts patients at some more risk of earlier death. The final significant predictor of longevity among mildly dependent patients was marital status.

In conclusion, in the assessment of the patient’s survival as a predicting factor in care, four care dependency factors were related to survival. Survival prognosis varied with the level of care dependency, notwithstanding the fact that care dependency is not the cause but the effect of health problems. Within this scope, (nursing) care should primarily focus on helping patients to minimize the effects of associated co-morbidity, to perform those activities that contribute to stabilization or decrease of care dependency, and, as Henderson repeatedly emphasized (26,27), to help patients to die with dignity when death is inevitable. From a methodological point of view, a possible limitation in generalizing the findings of this study is that the data were obtained from patients of one particular psychogeriatric nursing home and that the patients in the panel were all women. Therefore, further longitudinal research is needed to find whether the patient group studied is representative of the total population of Alzheimer’s disease patients. Apart from that, studies are needed to investigate longitudinal changes and differences in care dependency in order to predict care dependency in Alzheimer’s disease. Outcomes of such studies may add to the understanding of the specific dimensions of patient dependency on (nursing) care and of factors that are related to nurses’ abilities to decrease or stabilize dependency of their patients.

References


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