Their last 6 months: suffering and survival of end-stage dementia patients

Bechor Zvi Aminoff, Abraham Adunsky

Geriatric Division, Sheba Medical Center, Tel-Hashomer 52621, Israel

Address correspondence to: A. Adunsky. Tel: (+972) 52 6666550. Fax: (+972) 3 5303411. Email: eadunsky@hotmail.com

Abstract

Objective: to study possible interrelations existing between the Mini-Suffering State Examination (MSSE) scale and survival of end-stage dementia patients.

Methods: a cohort study of 252 end-stage dementia patients with a 6-month follow-up period, conducted in a Division of Geriatric Medicine of a general hospital. We included 134 consecutive bedridden end-stage dementia patients admitted during a 36-month period, and surviving in the ward for <6 months. Interrelations between survival and admission MSSE scores were studied.

Results: compared with patients surviving ≥6 months, those dying within 6 months were significantly older (P = 0.014). Mean survival time was 57.76 ± 9.73 days for the low MSSE score group (29 patients, MSSE 2.24 ± 0.99), 44.70 ± 5.99 days for the intermediate MSSE score group (53 patients, MSSE 4.92 ± 0.83) and 27.54 ± 4.16 days for the high MSSE score group (52 patients, MSSE 8.06 ± 1.00). Differences between the survival times of these three MSSE score groups were statistically significant (Kaplan–Meier Analysis Log Rank P = 0.0018, Breslow P = 0.0027). The Cox proportional hazard model of survival showed a significant interrelation of high MSSE scores and shorter survival (P = 0.013).

Conclusions: documentation of a high-suffering level by the MSSE scale helps in identifying end-stage dementia patients expected to benefit from enrolment into a palliative care setting.

Keywords: dementia, end-of-life, hospice, suffering, survival, elderly

Introduction

Each year, over 33 million people in the world would need relief from suffering and palliative care [1]. An estimated 1.8 million people in the United States are in the final stages of dementing illnesses, such as Alzheimer’s disease and vascular dementia, and will ultimately require end-of-life care. Many are expected to spend the last phase of life in various settings of palliative care, where issues of quality of care and satisfaction for patients and families are of crucial importance. For these patients, regardless of life expectancy, palliation is often the primary goal of care.

Despite these considerations, only a small minority of non-cancer patients access specialist palliative care services, which stems, partially, from differences in both enrolling criteria and financial coverage between different countries, in particular between the United Kingdom and the United States. When St Christopher’s hospice was first opened, it was envisaged that service would be accessible to non-cancer patients, including those with dementia; yet, cancer remained the dominant diagnosis group [2].

Unfortunately, many residents of long-term facilities are dying with advanced dementia without receiving the optimal palliative care [3]. In recent years, the elements of excellent end-of-life care have been better defined and include various elements of palliative care in order to minimise suffering levels [4, 5]. The decision-making process regarding palliative or hospice-like approach for end-stage dementia patients is complicated because data on appropriate criteria to assess the suitability of hospice care are limited, resulting in <2% of patients with advanced dementia being involved in hospice-care programmes [6]. One of the enrolment criteria identified by the American Medicare Hospice Benefit is a life expectancy of <6 months [7]. The narrow eligibility criteria ensure that the majority of enrollees will die within 6 months, excluding a substantial proportion of persons with advanced dementia who also die during that period.

Several studies have investigated the 6-month survival of persons with a primary diagnosis of advanced dementia [8, 9].
The National Hospice Organization eligibility guidelines for patients with dementia are based primarily on the Functional Assessment Staging (FAST) criteria [10], which have been heavily criticized. A study on Dutch patients [11] has also suggested that the Hospice Medicare Guidelines are not valid for predicting survival in late dementia. More recently, a risk score based on 12 variables from the Minimal Data Set (MDS) proposed more accurate estimates of 6-month mortality for nursing-home residents suffering from advanced dementia than existing prognostic guidelines [12].

Palliative care is aimed at relieving suffering and improving the quality of life of patients with advanced illnesses, and should involve a routine and standardized symptoms assessment [13]. Defining and measuring these aspects is difficult, albeit crucial, because these patients are unable to recognize and communicate verbally with family members, are totally dependent on others in daily activities and experienced repeated health problems.

Suffering is traditionally viewed as a state encompassing psychological distress, spiritual concerns and various aspects of physical pain. There is an insufficient clinical evidence for suffering in dying dementia patients, which may lead to inappropriate evaluation and insufficient palliative treatment.

The recently developed Mini-Suffering State Examination (MSSE) is a practical clinical scale used for the assessment of suffering level in end-stage dementia [14]. Its use permits better assessment and control of suffering in end-of-life, and is easily integrated into daily ward routines. It has the potential of monitoring the extent of suffering [15] so that inadequate medical and nursing treatment, negligence and mistreatment may be approached, and steps be taken to change treatment protocols and diminish the patient’s level of suffering. Both physicians and nurses may easily use the MSSE, which is brief and friendly, taking <10 min to administer.

The purpose of this study was to investigate true end-stage dementia patients, i.e. those expected to survive <6 months, and who actually die within this time period. The study evaluated the possible interrelations existing between the level of suffering, as assessed by the MSSE scale, and survival of these end-stage dementia patients.

Methods

A total number of 252 consecutive end-stage dementia patients were admitted to the long-term geriatric ward of the Division of Geriatric Medicine. Patients were referred from acute care departments of the general hospital during a 3-year period of study. All caregivers were interviewed on the day of the patient’s admission, and a full medical history was obtained. Data were also collected from letters of referring physicians and general practitioners. Diagnosis of dementia was made according to the DSM-4 Revised criteria [16]. We included patients with Alzheimer’s disease, vascular dementia and dementia of other origin. Inclusion criteria included severe dementia interfering with verbal communication (Mini-Mental State Examination score 0) [17] and complete dependency in all activities of daily living and functional movement activities, recorded by a minimal score (18 points) of the Functional Independence Measure (FIM) [18].

The medical condition of 118 patients was stable, and most of them were discharged from the ward to their previous living arrangements. The final analysis included only the remaining 134 (74 males and 60 females) patients with very advanced dementia who did not survive the full 6-month period from admission to our ward. This group included 65 (48%) patients with Alzheimer’s disease, 51 (38%) vascular and post-stroke dementia and 18 patients (14%) with other dementia types. Such patients therefore comply with guidelines on hospice enrolment for advanced dementia patients [6] having a life expectancy of ≤6 months.

All patients were evaluated upon admission to the ward by the MSSE scale [14]. Briefly, it consists of 10 items related to levels of calmness, screaming, pain, pressure ulcers, malnutrition, eating disorders, performance of invasive procedures, stability of general medical condition, and the impression of medical staff and family regarding the patient’s level of suffering. Scores for each of the 10 items is 0 (normal) or 1 (abnormal), and total score ranges between 0 and 10, with higher scores reflecting high suffering levels of the patients. MSSE scores have been divided into three categories: low (0–3), intermediate (4–6) and high (7–10). This classification has previously been shown to represent distinct subgroups, with significant differences between them, which have been tested for validity and reliability [14]. In addition, we recorded data relevant to medical conditions such as important blood laboratory results (total protein, albumin, cholesterol, haemoglobin, total lymphocyte count and so on) and use of dementia-related medications such as narcotics, antipsychotics (Risperidone, Haloperidol, Tioridazine, Sulpiride and others), antidepressants and analgesics. The study protocol was approved by the local Institutional Review Board (IRB).

Statistical analysis

Comparisons between the three groups of patients defined according to MSSE scale (low, intermediate, high) were performed using a one-way Analysis of Variance (ANOVA) and chi-square tests, as applicable. Univariate Cox regression and Kaplan–Meier analysis examined the association between each parameter and survival. A multivariate Cox regression model was applied to the data to study simultaneously the independent relationship between each risk factor and survival. The model predicts the probability of surviving as a function of the explanatory variables. The statistical significance level was set to 0.05 and the SPSS for Windows software, Version 11.0, was used for the analysis.

Results

Mean age of patients was 82.9 ± 9.3. The general characteristics of the study population are presented in Table 1. Compared with patients surviving ≥6 months, those dying within 6 months were significantly older (P = 0.014) and included more male patients (P = 0.01) and patients with feeding tubes or gastrosomies (P = 0.02). These patients
also presented with lower admission haemoglobin ($P = 0.001$), total cholesterol ($P < 0.0001$) and albumin ($P < 0.0001$) levels. Total MSSE score upon admission to the ward was $5.56 \pm 2.42$ in patients dying within 6 months and $3.61 \pm 2.0$ in those surviving >6 months ($P < 0.0001$).

We have identified 29 patients with a mean MSSE score of $2.24 \pm 0.99$, 53 patients with $4.92 \pm 0.83$ and 52 patients with $8.06 \pm 1.0$ in the groups of low, intermediate and high level of suffering, respectively.

Mean survival time was shorter for those having higher MSSE scores upon admission to the ward. Survival time was $57.7 \pm 9.7$ days, $44.7 \pm 5.9$ days and $27.5 \pm 4.1$ days in the low, intermediate and high suffering levels, respectively. The differences between mean survival times among the three MSSE groups were statistically significant (Kaplan–Meier Analysis, Log rank $P = 0.001$, Breslow $P = 0.0027$) (Figure 1).

A univariate Cox regression analysis showed a statistically significant correlation between mean survival time and high MSSE scores ($P = 0.001$), the use of narcotics ($P = 0.014$), and the levels of total protein ($P < 0.0001$), albumin ($P = 0.001$) and cholesterol ($P = 0.001$) in those dying within 6 months after admission. There was no correlation between mean survival time of these end-stage dementia patients and low or intermediate MSSE scores, sex, use of nasogastric tube and percutaneous endoscopic gastrostomy, or with any other laboratory parameter or with other medications.

When a multivariate Cox proportional hazards model was applied to the data (Table 2), a high MSSE score (indicating a high-level of suffering) emerged as a major significant risk factor for death during the 6-month period ($P = 0.013$). Use of nasogastric tube ($P = 0.024$), and higher haemoglobin ($P = 0.044$), cholesterol ($P = 0.046$) and total protein ($P < 0.0001$) levels appeared to be ‘protective’ against shorter survival.

**Discussion**

The present study focused on the possible interrelations between the level of suffering as determined by the MSSE and survival of end-stage dementia patients. This issue is of interest for health care providers and policy makers concerned with the enrolment of patients into palliative care settings.

Our results on the interrelation of high MSSE scores with shorter survival period allow us to suggest that MSSE could serve as a key criterion for screening general hospital wards, nursing homes and community for those end-stage dementia patients with high levels of suffering and shorter survival. This is extremely important because difficulty in estimating survival of end-stage dementia patients is a serious barrier to provision of hospice care to such patients [19–22].

Mitchell et al. [12] have recently addressed the estimated prognosis for nursing-home residents with advanced dementia. However, their study comprised a high percentage of functionally non-dependent patients (74%) and a low percentage of bedridden patients (7.7%), thus representing a population that is not severely affected by a dementia syndrome. It is not surprising that these authors have found that the characteristics associated with poorer survival (such
as older age, greater functional impairment, male sex, cardio-
vascular disease, diabetes mellitus and poor nutritional sta-
tus) were identical to those identified within a general
demented population regardless of the stage of dementia
[23–25].

This study has investigated an end-stage demented
population rather than an advanced demented population.
Treatment of these patients is much more difficult,
lengthy and wears out medical and nursing staff as well as
families [26]. The difficulty lies within the complexity of
medical, nursing, cognitive, emotional, religious, ethical
and social problems. Despite intensive efforts of the med-
ical staff, deterioration is inevitable, and the level of suf-
ferring increases as the patient approaches his or her last
day of life [27]. Because a substantial number of end-stage
dementia patients in this study died in a high level of suf-
ferring, as evaluated by MSSE, it is essential that new
palliative treatment approaches be implemented for such
patients.

Many high-level suffering patients require emergency
decision-making changes in the treatment strategies to al-
leviate their suffering. One way to provide that care might be
the adoption of alternative strategies to deliver a com-
prehensive palliative care to this population. Operative options
to solve this problem may involve a classic hospice-like set-
ting; however, this may not be sufficient for those with
high-level suffering whose family members may ask for
more active treatment. For these, a setting designed to
encourage the implementation of a more active approach
aimed at reducing the various elements associated with suf-
ferring in these patients (such as better prevention of malnu-
trition, pressure ulcers, infections and so on) may be more
suitable. The indication for referral to this type of facility
(suffering relief settings) should be neither the cognitive,
functional and nutritional condition nor any other medical
problem but the need for a comprehensive, effective and
reliable care aimed at reducing the level of suffering.

MSSE is expected to improve the care of patients and
complies with the formal position statement from the
American Geriatrics Society on the care of the dying patient
[28] and the Canadian palliative care association [29].
Subsequent investigation is required to examine whether
it would be possible to minimise the level of suffering of
such patients and to seek additional ways for the preven-
tion of their suffering. Further prospective validation
would be helpful to assess the use of the MSSE in clinical
practice.

Key points

- High-level suffering is frequent in end-stage dementia
  patients.
- Higher suffering levels are associated with shorter sur-
vival periods.
- MSSE provides a useful clinical tool for the assessment
  of survival and may facilitate decisions regarding enrol-
  ment into palliative settings.

Funding

There was no external funding for this study.

Conflicts of interest

No conflicts of interest.

Ethical approval

The study was approved by the IRB.

References

6. Berger A. Palliative care in long-term care facilities: a comprehen-
10. Reisberg B. Functional Assessment Staging (FAST). Psychop-
11. Koopmans RT, Ekkerink JL, Van Weel C. Survival to late
350: 2582–90.
14. Aminoff BZ, Purits E, Noy S, Adunsky A. Measuring the suf-
ferring of end-stage dementia: reliability and validity of the Mini
Suffering State Examination. Arch Gerontol Geriat 2004; 38:
123–30.
15. Aminoff BZ, Adunsky A. Dying dementia patients: too
much suffering, too little palliation. Am J Hosp Care 2005;
17. Folstein MF, Folstein SE, McHugh PR. “Mini-mental state”.

600
Favourable effects of exercise training on NT-pro-BNP plasma levels in elderly patients after acute myocardial infarction

FRANCESCO GIALLAURIA, ROSA LUCCI, ANNA DE LORENZO, MARIANTONIETTA D’AGOSTINO, DOMENICO DEL FORNO, CARLO VIGORITO

Department of Clinical Medicine, Cardiovascular and Immunological Sciences, Cardiac Rehabilitation Unit, University of Naples Federico II, Naples, Italy

Address correspondence to: F. Giallauria, Department of Clinical Medicine, Cardiovascular and Immunological Sciences, Cardiac Rehabilitation Unit, University of Naples Federico II, Via S. Pansini, 5, I-80131 Naples, Italy. Tel: (+39) 081 7462639, Fax: (+39) 081 7462639. Email: giallauria@libero.it

Abstract

Background: regional or global impairment of left ventricular (LV) systolic or diastolic function leading to increased LV wall stress results in increased circulating levels of N-terminal pro-brain natriuretic peptide (NT-pro-BNP).

Objective: this study aims at evaluating the effect of exercise training (ET) on NT-pro-BNP plasma levels in older patients recovering from acute myocardial infarction (AMI).

Design: prospective randomised study.

Setting: Academic Medical Centre.

Subjects: forty older patients (35 males and 7 females) who experienced AMI.

Methods: patients were randomised into two groups, each composed of 20 patients: Group A were enrolled in a 3-month exercise-based cardiac rehabilitation (CR) programme and Group B were discharged home with generic instructions to continue physical activity. NT-pro-BNP, cardiopulmonary and Doppler-echocardiographic parameters were measured at baseline and at 3-month follow-up.