Behavioral and Physiological Observations During the Day: How Patients with Advanced Dementia Spend Time in a Care Facility

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Abstract: Objective: To clarify how patients with advanced dementia in a care facility spend time during the day through sequential observation of activities. Methods: Activities of 12 patients with dementia were observed using an original form for monitoring their behavior and applying electroencephalograms (EEGs) with electrooculograms (EOGs) to identify awake and sleep states. Results: The amount of time in an awake state was significantly longer than in the other states, although the awake/sleep rhythm fluctuated in all participants. The subjects were mainly occupied with “unpurposed period”, in which they were inactive, although fully awake. Conclusion: Through reporting daily activities and awake/sleep states during the daytime in patients with dementia in a care facility, serial monitoring of behavior and the recording of biological activity revealed precise knowledge of the actual daily situation of patients with advanced dementia.

Key words: occupational balance, dementia, activity, lifestyle

Introduction

A considerable number of people who suffer from dementia are living in care facilities in Japan, where 23.3 and 11.6% of residents were over 65 and 75 years old, respectively, in 2011 (Japanese Ministry of Health, Labour and Welfare, 2011a). Occupational therapy is important in such a situation, and occupational therapists are required to have sufficient knowledge of the elderly with dementia (Padilla, 2011).

Again, in Japan, the number of patients living in care facilities has markedly increased in recent years. While the number of registered elderly care facilities and patients in such facilities in 2000 was 10,992 and 648,559, respectively, they were 11,319 and 805,889 in 2009 (Japanese Ministry of Health, Labour and Welfare, 2011b). Therefore, how occupational therapists provide interventions for patients with dementia in care facilities as well as those in the community is an important issue. Although there are many problems to be solved in care facilities, interventions for so-called bed-ridden elderly patients have been the most closely considered over the last decade. The development of percutaneous endoscopic gastrostomy (PEG), instead of intravenous hyperalimentation in the 1990s (Shintani, Fumimura, Shiigai, Nakamura, Kataoka, Yokoi, & Ariyasu, 2001), has certainly changed the situation for these patients (Higaki, Yokota, & Ohishi, 2008; Yamaguchi, Hoshiyama, & Takano, 2011). Although the potential benefit of PEG to improve a patient’s nutritional condition has been emphasized, the role of treatment in patients with advanced dementia has recently been debated (Garrow, Pride, Moran, Zapka, Amella, & Delegge, 2007; Gillick & Volandes, 2008; Sanders, Leeds, & Drew, 2008; Freeman, Ricevuto, & DeLegge, 2010; Yamaguchi et al., 2011). Occupational therapists in Japan have been struggling to find a better intervention for bed-ridden patients, and the number of such patients is still increasing (Suzuki et al., 2010). Therapists may easily imagine that patients with advanced dementia and poor oral intake exhibit little activity. However, there is a dearth of information regarding their actual activity in care facilities during...
The objectives of the present study were to investigate how the elderly with advanced dementia spend their time in a care facility, and to provide basic information for therapists in care facilities on activities during the day of patients with advanced dementia. Jacobs, Ancoli-Israel, Parker, & Kripke, (1989) previously investigated 24 hour sleep-awake patterns of the elderly in a nursing home by observing their wrist movement with an approximate evaluation (one value per hour). However, determining awake/sleep states in elderly patients with dementia through open observation is not practical, since those patients often make only a few movements even in awake states. For this purpose, continuous behavioral and biological observations of patients were conducted. We continuously recorded and quantified their activities and biological signals using electroencephalography (EEG) and electrooculography (EOG), as well as behavioral observation during the day. The EEG signals with EOG recording have been one of the most reliable methods to document the awake/sleep status (Martin, Johnson, Viglione, Naitho, Joseph, & Moses, 1972). We considered that precise knowledge of patients’ biological activities would enable us to identify efficient interventions for them from cognitive functional aspects. This pilot study aims to clarify the activity of patients with advanced dementia to help them lead a more balanced life.

Materials and Methods

We collected personal profiles, and observed and recorded the behaviors of the participants every 2.5 min starting before breakfast (7:40) to before supper (18:00) on a single day (Wednesday). We also continuously recorded EEG and EOG during the observation period.

Participants

Twelve patients with dementia in a care facility participated in the present study. They were comprised of one male and eleven females, ranging in age from 75–89 years (mean 80.4; SD ± 4.9). The mean admission period of the patient ranged from 11.8 months to 73.4 months (mean 54.1; SD ± 21.0). All subjects suffered from advanced dementia, and were wheelchair bound. The average score of the 100-point Barthel Index (BI) (Shah, Vanclay, & Cooper, 1989) for all patients was 14.2 ± 17.7 (± SD). A summary of the participants is shown in Table 1.

No participants had a history of focal cortical symptoms, but evaluating precise higher brain functions such as agnosia and apraxia proved difficult due to their poor response at the onset of the study. Participants with specific causes of dementia, i.e., massive cerebral infarction/hemorrhage, encephalitis, toxic and metabolic encephalopathy, brain tumors, and other focal intracranial lesions, were excluded. Therefore, the participants suffered from slowly progressive dementia, including senile dementia of the Alzheimer type (SDAT) and dementia with Lewy bodies (DLB), although further diagnostic examination was not applied. None of the participants showed involuntary movements of the head, neck, or extremities, and ocular movement was not disturbed by physical examination at the bedside. They did not show major problems related to behavioral and psychological symptoms of dementia (BPSD) at the time of the study, which often cause difficulty in care, and hence increase the caregiver burden (Finkel, 2000).

The mean Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) score of the participants was 7.8 ± 5.9. Written informed consent to participate in the study was obtained from the families, and, if possible, from all participants prior to commencing the study. The study was approved by the Ethical Committee of Nagoya University, School of Health Sciences, based on the Helsinki declaration (World Medical Association,
Participants were all inpatients in a mid-sized care facility, where approximately 100 elderly patients with and without dementia were provided with medical care and underwent rehabilitation with occupational and physical therapists.

**Experiment design**

1. Continuous recording of behavioral activities

   We selected Wednesday as the day of the observation, since bathing and outside activities were not scheduled on that day. From 8 a.m. to 5 p.m., we carefully observed and described each participant’s behavior every 2.5 min using an original monitoring sheet (Table 3) because some activities were completed in less than a few minutes. We recorded the location of the patients, the patients’ postures, their activities, and anything worthy of note; e.g., talking with a caregiver, watching television, eating, and dressing (Table 4).

2. Continuous recording of biological activities

   A wireless amplifier was employed so as not to disturb each participant’s movements during the recording period. EEG signals were recorded from two scalp areas, Oz and C3, with referential electrodes of the linked mastoid process, using surface electrodes which were 7-mm silver-silver chloride disc electrodes. Those recording areas were selected to observe basic alpha activity and sleep-specific responses, the vertex potential, and sleep spindle. EOGs were recorded from the right eye by placing electrodes 2 cm below the infra-orbicular edge and 2 cm lateral to the lateral canthus of the right eye. Impedance between electrodes was kept at less than 10 kOhm. The EEG and EOG signals were recorded with an initial band-pass filter from 1.6 to 60 Hz and transferred through

**Table 2. Scoring criteria for awake and sleep states**

<table>
<thead>
<tr>
<th>Awake/Sleep state</th>
<th>EEG findings</th>
<th>EOG findings</th>
<th>EMG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-awake (FA)</td>
<td>Beta or alpha activity</td>
<td>Blinking or saccadic eye movement</td>
<td>Bursts of EMG</td>
</tr>
<tr>
<td>Rest-awake (RA)</td>
<td>Alpha activity</td>
<td>Loss of blinking or saccadic eye movement</td>
<td>Spontaneous bursts of EMG</td>
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<tr>
<td>Drowsy (S1)</td>
<td>Suppression of alpha activity, sporadic vertex potentials</td>
<td>Loss of blinking or saccadic eye movement</td>
<td>Silent EMG</td>
</tr>
<tr>
<td>Light sleep (S2)</td>
<td>Spindles</td>
<td>Loss of blinking or saccadic eye movement</td>
<td>Silent EMG</td>
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</tbody>
</table>

**Table 3. Monitoring sheet for behavioral observation**

<table>
<thead>
<tr>
<th>Place</th>
<th>Posture</th>
<th>Time</th>
<th>Activity</th>
<th>Notable observation</th>
</tr>
</thead>
<tbody>
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</table>


**Table 4. All activities shown during observation for every participant**

<table>
<thead>
<tr>
<th>Category</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>Dressing (1)*, Eating (12), Medical treatment (6), Oral hygiene (11), Personal device care (1), Toilet hygiene (12), Transfer (12)</td>
</tr>
<tr>
<td>Purposeful</td>
<td>Conversation (7), Watching television (2), Afternoon tea (2), Walking around inside (1)</td>
</tr>
<tr>
<td>Un-purposed</td>
<td>(12)</td>
</tr>
<tr>
<td>Rest</td>
<td>Sleep (11)</td>
</tr>
</tbody>
</table>

(* the number of patients who participated in the activity.)
a wireless amplifier (WEB-5000, NIHON-KOHDEN, Japan) with an analog to digital converter (ADC) (CSI-320312, Interface Co., Japan). The data were digitized at 1.0 KHz to store on a personal computer.

3. Data analysis

All observed activities were recorded and divided into four categories: activities of daily living (ADL), purposeful activities (work, productive activities, and leisure), un-purposed activities and sleep. We referred to the uniform terminology defined by the American Occupational Therapy Association for categorization (Rockville, 1979; American Occupational Therapy Association, 1994, 2004). The category of ADL included grooming, oral hygiene, bathing/showering, toilet hygiene, personal device care, dressing, feeding and eating, medication routine, and health maintenance. The category of purposeful activities included both “work and productive activities” and “play and leisure activities”. The other period when patients did nothing was categorized as an unpurposed period. The period of time in each activity category was expressed as a percentage of the recording period, since the total recording period varied in each participant, as described in Results.

Biological signals were also evaluated every 2.5 min. Awake and sleep states were investigated based on EEG signals and were evaluated based on the scoring system of Rechtschaffen & Kales (1968), although the score was partially modified using the EOG data. Full-awake (FA), rest-awake (RA), drowsy (S1), and light sleep (S2) states were defined as shown in Table 2.

From EOG signals, the period of time spent blinking or showing step-wise rapid (saccadic) eye movement, corresponding with the full-awake state, was measured. Since blinking and saccadic eye movements could not be separated on EOGs, we measured the time period showing both eye movements.

We compared BI or MMSE and the amount of time in an awake state using Pearson’s correlation coefficient test. We also compared the time period of FA, RA, and sleep with Student’s t-test. P-values less than 0.05 were considered significant.

The awake/sleep score was determined every 5 min: i.e., FA = 5; RA = 3; sleep (S1 or S2) = 1. The mean awake/sleep score every 20 min from 07.40–17.00 hours was calculated and described as a chart for each participant.

Results

All activities and biological signals were successfully obtained from all patients. The total recording period was 523 (8 hours and 43 min) ± 56 min (SD). Since the light-sleep state (S2) was determined by spontaneous sleep spindles, it was difficult to identify the exact onset and end of S2 during the recording period. Thus, S1 and S2 were put together and determined as a sleep state.

We also calculated the amount of time for FA, RA, and sleep during the entire recording period (Fig. 1). The average percentage of the FA and sleep states was approximately 80% and 20%, respectively. The RA status period was minimal. The patients were fully awake for significantly longer than for sleeping or resting while awake during the day. There was no significant difference between the resting while awake and sleep states. The correlation between BI or MMSE and the time period of FA was not significant. Sequential changes in the awake/sleep score during the day for all participants are shown in Fig. 2. The awake/sleep rhythm fluctuated in all participants, and the awake state was mostly maintained around meal times.

All activities performed by every patient were dressing, eating, medical treatment, oral hygiene, personal device care, toilet hygiene, and transferring (ADL), afternoon tea, conversation, walking around the facility, and watching television (purposeful activities), and sleeping. The period in which patients spent their time inactively was divided into an unpurposed category (Table 4).

The percentage of the four categories performed by each patient is shown in Fig. 3. The percentage for the category of ADL was around 30% in the twelve patients. Purposeful activities were shown in 8 patients, and the
The percentage was less than 12%. The percentage of time in the unpurposed period was the highest in 11 patients, ranging from approximately 40 to 70%. Sleep was noted in 11 patients. The percentage of unpurposed and sleep categories totaled more than 70% in all patients.

According to the results of EEG and EOG, the unpurposed periods consisted of 2 kinds of awake/sleep states: FA and RA. Four patients were fully awake during the unpurposed period, and the others were fully awake during more than 90% of the unpurposed period. Thus, all patients spent their time inactively during the un-purposed period, even though they were completely awake.

**Discussion**

In the present study, we investigated the daily performance and awake/sleep states of patients with dementia in a care facility during a single day. To our knowledge, such detailed observations have not been reported. The results are 1) a fully awake state remained, but the awake/sleep rhythm fluctuated except for meal times; 2) the patients were occupied by just a few activities except for ADL; and 3) the un-purposed period was the longest in almost all patients. All patients were fully awake during that period.
Clinicians may assume that elderly patients with advanced dementia lack activity and tend to sleep during the day. However, there is no data regarding how long and how often such patients sleep during the day. In fact, patients often stay awake during the day, although their awake/sleep states fluctuate. Jacobs et al. (1989) measured awake-sleep patterns in 19 elderly patients with and without dementia in a care facility, but they did not separately record the patterns for patients with advanced dementia. This is the first report, as far as we know, which investigated the awake/sleep states in elderly patients with advanced dementia by continuous recording of biological signals.

The relationship between activity and cognitive function in the elderly has been reported (van Gelder, Tijhuis, Kalmijn, Giampaoli, Nissinen, & Kromhout, 2004; Weuve, Kang, Manson, Breteler, Ware, & Grodstein, 2004; Klusmann, Evers, Schwarzer, Schlattmann, Reischies, Heuser, & Dimeo, 2010; Leung, Fung, Tam, Lui, Chiu, Chan, & Lam, 2011). Decreasing activity leads to a decline in cognitive function, and leisure or cognitive activities could reduce the risk of dementia (Verghese et al., 2003; Helzner, Sarmaceas, Cosentino, Portet, & Stern, 2007; Hall, Lipton, Sliwinski, Katz, Derby, & Verghese, 2009). Although physical activities do not always show a link to cognitive impairment (Laurin, Verreault, Lindsay, MacPherson, & Rockwood, 2001), reduced physical activity could be a risk factor for Alzheimer’s disease (Larson, 2008; Lautenschlager et al., 2008). Thus, maintaining an active daily life, especially linked with a positive emotional state, has been considered an important factor maintaining the quality of life (QOL) of elderly patients (Skevington, Lotfy, O’Connell, & WHOQOL Group, 2004), although evaluation of QOL of patients with advanced dementia is not easy (Schölzel-Dorenbos et al., 2007). Therefore, therapists must identify the most appropriate intervention for low-activity patients with advanced dementia to prevent functional decline and maintain their QOL.

The patients in the present study spent most of their time without purpose, although they were in a fully awake state. This is the most significant finding of the present study. Because they were not asleep but in an awake state maintaining the awake/sleep cycle (Sloane et al., 2007; Flick, Garms-Homolová, & Röhnsch, 2010). Thus, adequate occupational intervention may reduce awake/sleep fluctuation in these patients. However, keeping the patients awake is not the sole solution. Previous research pointed out a similar issue in patients with advanced dementia, who spent the greater part of their day unoccupied (Perrin, 1997). They also stated that simply facilitating intervention might not be sufficient, but improving the skills and qualities that individual staff members bring to their interventions was important (Perrin, 1997). Occupational therapy for daily activities, such as washing, dressing sanitary services and eating improved functional scores (Baldelli et al., 2007).

Previous studies also referred to the lifestyle or life balance in the field of occupational therapy (Jackson, Carlson, Mandel, Zemke, & Clark, 1998; Pentland, & McColl, 2008). However, in Japan, the number of patients with advanced dementia has increased far more rapidly than any other country, and the recent situation regarding care facilities for patients with advanced dementia is rapidly changing in terms of quantity and quality. The number of therapists and caregivers is far from enough (Japanese Ministry of Health, Labour and Welfare, 2011b), and how such patients with advanced dementia should be managed with occupational therapy in care facilities is still being debated. It is clear that occupational therapists experience difficulty with elderly patients suffering from advanced dementia who lack activity or occupation. Further research may be required to investigate the criteria for a well-balanced life for elderly patients with advanced dementia, in order to know how much intervention and rest time should be provided.

Limitations of the present study were an inability to propose a clear solution to improve the status of the patients with dementia, as described in the previous paragraph. The present study reported only the behavioral and physiological aspects of the patients. Effects of intervention on the states of patients, variation of the data among facilities, psychological evaluation of the patients, and theoretical and practical proposals to improve QOL of the patients and caregivers should be investigated in the future.

The present study reported daily activities and the awake/sleep status during the daytime in patients with dementia in a care facility. Serial monitoring of behavior and recording of biological activity revealed precise knowledge of actual daily situation in patients with advanced dementia.

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