

Memory rehabilitation of an amnesic patient following limbic encephalitis and a role of family members: A case report

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We describe problems in daily living that arose in a 46-year-old man with severe amnesia following limbic encephalitis. Amnesic symptoms changed from stage I (difficulty in memory retention) to stage II (loss of continuity of memory) and finally to stage III (paramnesia and confused sequence of events), significantly affecting his ability to function. Questionnaire response assessment, directly observed behavior, neuropsychological testing, and especially interviewing permitted qualitative assessment of clinical changes, promoted patient insight into the memory disturbance, and enhanced motivation to use a memory notebook. Additionally, the family gained a better understanding of the disorder, made appropriate environmental modifications, and provided other necessary assistance. Episodic memory improved, and the memory notebook served as an effective compensatory tool. However, disturbance in prospective memory did not improve, and was not compensated adequately by use of the notebook. Anxiety and significant impairment of everyday functioning resulted. Long-term supportive intervention at home was necessary. The patient's wife in particular needed to make environmental adjustments and aid him in use of the notebook.

Key words : Amnesia, Episodic memory, Prospective memory, Neuropsychology, Rehabilitation, Memory notebook, Temporal lobe

INTRODUCTION

Everyday memory is an area of growing interest [2]. Because of difficulty in quantitatively assessing this function and because of differences between individual patients' environments, the impact of memory deficits on everyday life and the effectiveness of rehabilitation on everyday memory remain to be clarified.

Neuropsychological management of memory problems consists of internal strategies and external compensations [23]. Internal strategies, shown to be effective in laboratory studies, include visual imagery, PQRS (preview, question, read, state and test) strategies and initial (first letter) mnemonic approaches. Although the internal strategies permit the patient to learn new information [21], their range is limited; it has not been accepted that such training will provide a significant improvement in the

general level of memory [4, 22, 24]. Richardson (1992) [17], though appreciating the utility of the visual imagery approach, recommended that the patient's efforts should be directed toward improving "metacognitive skills" and gaining knowledge in a field of practical value instead of seeking proficiency at strategies which are often not used in actual everyday settings. Thus, the realistic goal of memory rehabilitation at present appears to assist the patient to build up knowledge in a specific field required in daily life by using external memory devices.

With reference to studies done in Japan of external memory devices, Honda *et al.* (1992) [9] presented a program consisting of environmental adjustment and the use of a memory notebook; Nunotani *et al.* (1993) [15] described a rehabilitation program for a patient who had rupture of an aneurysm at the origin of the anterior communicating artery resulting in severe amnesia however

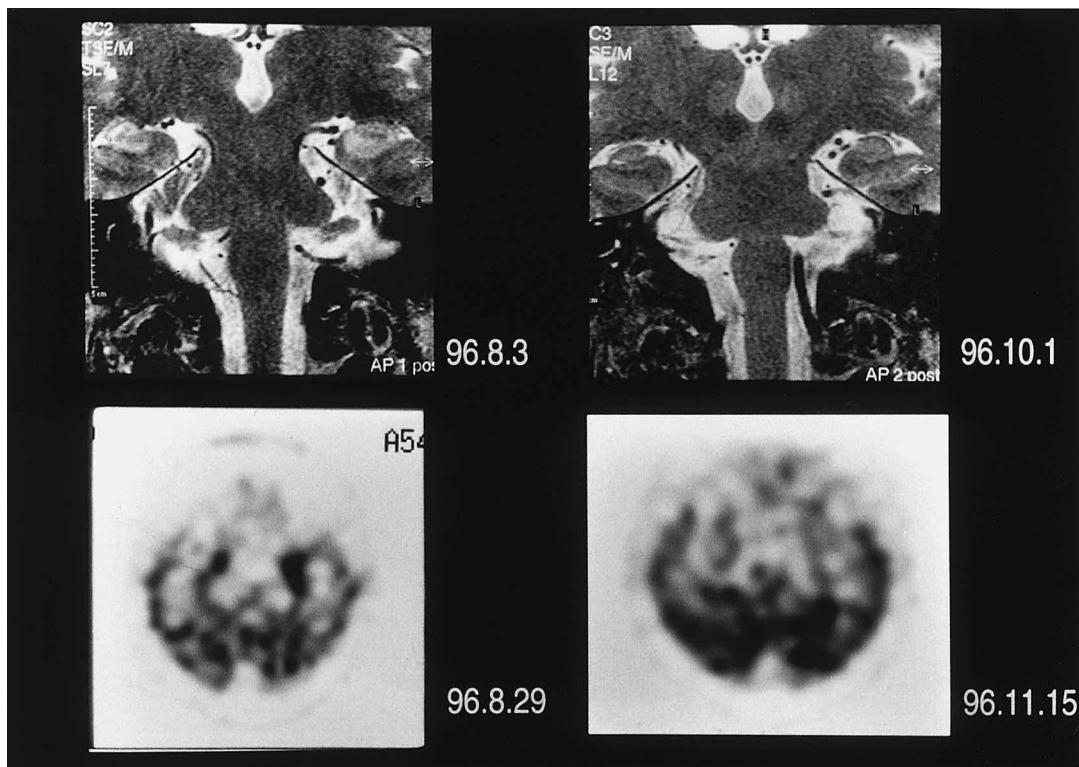


Fig. 1 Brain imaging: Coronal T2-weighted magnetic resonance (MR) image and single-photon emission computed tomography (SPECT) image using ^{99m}Tc -hexamethyl propylene amine oxime (^{99m}Tc -HMPAO). The left side of the image corresponds to the right side of the actual brain.

retaining various intellectual capacities. The patient referred to a notebook when prompted by a timed alarm. However, some patients with amnesic disorders lack awareness of their deficits, and, in these cases, memory training using external compensatory strategies has been reported to be difficult [10].

Burke *et al.* (1994) [3] described the important points in memory notebook training as a compensatory strategy for neurological patients: 1) raising self-awareness of memory deficits, while minimizing psychological resistance; 2) offering individualized memory notebook training, which aids in seeing the notebook as a tool for maximizing independence; and 3) ensuring support after discharge from the hospital, which is necessary for the maintenance of optimal performance.

A literature review by the authors revealed few long-term follow-up studies of patients with severe amnesic disorders, investigating the problems they face and the utility of external compensatory strategies in coping

with various everyday issues. Unfortunately, effectively helping amnesic patients and their family members is still a matter of trial and error in clinical practice. In this paper, we describe the clinical course and post-discharge problems in everyday life of a man with severe amnesia which followed limbic encephalitis and discuss how to evaluate and support such patients.

I. Case presentation

History of present illness. A 46-year-old man was admitted to the hospital with a diagnosis of amnesic syndrome on May 22, 1996 and was discharged, as symptoms subsided, on June 7, 1996. He was readmitted on August 2, 1996 because of worsening of symptoms beginning in mid July. He was diagnosed as having an idiopathic limbic disorder and rehabilitation was initiated in October.

Education and occupational background. He graduated from a senior high school and was a white-collar worker.

Table 1 Changes in neuropsychological test values.

| Test / Date | Oct. 96 | Dec. 96 | Mar. 97 | Aug. 97 | Dec. 97 |
|----------------------|----------------|--------------|---------|--------------|---------|
| | Rehab. Started | Discharged | | | |
| TMT (A) | 2 min 38 sec | 2 min 0 sec | | 1 min 31 sec | |
| TMT (B) | 3 min 3 sec | 2 min 33 sec | | 2 min 43 sec | |
| PASAT 1 sec interval | 13/60 | 18/60 | | 21/60 | |
| PASAT 2 sec interval | 7/60 | 21/60 | | 22/60 | |
| Miyake VRT | | | | | |
| Related Pairs | 4-2-5 | 7-6-7 | 8-9-8 | 9-8-8 | 9-9-9 |
| Unrelated Pairs | 0-0-0 | 0-0-0 | 0-0-0 | 1-3-4 | 4-6-6 |
| Benton VRT | | | | | |
| (Correct/Incorrect) | | | | | |
| Immediate Recall (A) | 3/11 | | 3/16 | 5/7 | 4/16 |
| Delayed Recall (D) | 4/18 | | 5/10 | 5/10 | 5/12 |
| Rey's Figure Test | | | | | |
| Copying | | 35/36 | | 36/36 | |
| Immediate Recall | | 4/35 | | 12/36 | |
| KWCST | | | | | |
| No. Completed | 3 | 5 | 5 | | |
| Intelligence Test | WAIS-R | | | RCPM | |
| | VIQ 98 | | | 34/36 | |
| | PIQ 95 | | | | |
| | FIQ 97 | | | | |

TMT, Trail Making Test; PASAT, Paced Auditory Serial Addition Test; Miyake VRT, Miyake Verbal Retention Test (Ten pairs of Japanese words are given. Trials are repeated three times. Data are shown in series, with trials separated by hyphens. Normative values are 8.5-9.8-10 for related pairs, and 4.5-7.6-8.5 for unrelated pairs.) [14]; Benton VRT, Benton Visual Retention Test; KWCST, Wisconsin Card Sorting Test (Keio University version) [11]; WAIS-R, Japanese Wechsler Adult Intelligence Scale-Revised; RCPM, Raven's Coloured Progressive Matrices.

Laboratory assessment. T2-weighted magnetic resonance (MR) images depicted areas of increased signal intensity bilaterally in the medial regions of both temporal lobes, with the left lobe being enlarged compared with the right. Single-photon emission computed tomography (SPECT) revealed hot spots in the corresponding sites, more markedly on the left than the right (Fig. 1).

Hematological data on tumor markers, i.e., carcinoembryonic antigen (CEA), carbohydrate antigen (CA) 19-9, γ -seminoprotein (γ -Sm), acid phosphatase (ACP) and prostate antigen (PA), were within the normal range. Vitamin B1, B12 and folic acid concentrations were within the normal range. Results of Hu and Yo antineuronal antibody studies were negative. Cerebrospinal fluid (CSF)

examination provided negative results for all items tested: antibodies against herpes simplex virus and cytomegalovirus as well as their DNA, varicella virus antibody, Epstein-Barr virus antibody, staining by Burri's India ink method and fungal and bacterial cultures. CSF cytology showed class I (no abnormality). No abnormalities were found on chest X-ray films, barium enema X-rays or systemic γ -ray scintigraphy.

Neuropsychological findings. Table 1 shows the results of the initial examination. Details of each test are described in the literature [11, 12, 14]. The memory picture was: immediate memory was well-preserved, allowing recall of 6 digits in the conventional order and 5 digits in the reverse order; semantic memory was not impaired; a priming effect

(Tulving 1990) [20] was noted with word completion tasks; and procedural memory appeared normal, since a decrease in the number of errors was observed on repetition with mirror image drawing (tracing a figure while looking at its image in the mirror). Procedural memory (a motor learning task) was examined using a commercially available testing device (Model 141, Takei Kiki Kogyo, Tokyo, Japan). However, the patient showed severe disturbance in remembering faces, places and episodes; he said he was unable to recognize the training room, which he visited regularly.

Retrograde amnesia extending from 4 years before onset of the present disorder was manifested by patchy memory of events. There was no evidence of aphasia, apraxia or agnosia. Disorientation to both time and place and inadequate insight into his deficits were noted. He often slept in the ward through scheduled training hours, being unaware of the starting time.

These findings strongly indicated the diagnosis of typical amnesia with severe disturbance in episodic memory, though his attentional and frontal lobe functions and the level of intelligence were only slightly impaired.

II. Rehabilitation program following admission and clinical course

After the initial assessment, memory notebook training was conducted for about a month starting in October, but without good results. Then another training program, arranged according to the method of Nunotani *et al.* (1993) [15], was started in November, with a timed alarm used as an aid to help form the habit of using the memory notebook. The patient was also offered training on remembering the short route between the ward and training room. After a month's training in collaboration with ward nurses, nurse's aids, occupational therapists and the patient's wife, he learned to make notations of his activities in the notebook without help of the alarm. He was able to recognize the time to start training and to come to the room, seldom losing his way. His awareness of the impairment improved. He was discharged and went home in December. He was provided with speech therapy (ST) and occupational therapy (OT) as an outpatient twice a month.

III. Outpatient rehabilitation program and clinical course

Objective.

The outpatient rehabilitation program was designed to raise awareness of the memory impairment, to help the patient develop and maintain the habit of positive use of the notebook in daily life and to advise his family on how to support him in problems of daily living.

Content.

1. Everyday memory was assessed through self-reports (interviews and questionnaires) of both the patient and spouse, clarifying routine problems. Changes in memory disturbance were explained to them occasionally as feedback.

2. Support of the patient

Patient support consisted of: 1) assistance in maintaining the habit of carrying a systematically arranged portable notebook of B7 size (91 × 128 mm) in a waist pouch, which was smaller than the memory notebook of B5 size (182 × 257 mm) provided previously while he was in the hospital; 2) teaching the efficient use of the notebook by checking what he had written during his daily life and whether he could utilize the information written in the notebook during ST and OT treatment sessions; 3) making him perform a series of activities making use of the well-retained procedural memory in OT, where he was instructed to record the last activity of the session and where he had put the project he had worked on, thus encouraging him to work independently; and 4) promoting the development of accurate insights into memory deficits through interviews.

3. Support for his wife

Such support consisted of: 1) advice on how to modify the environment (drawing up a schedule, keeping various articles in specified places, etc.); 2) advice on how to assist his disturbed behavior due to memory impairment (prompting him to remember what to do, but trying to reduce the frequency of such prompts to promote independent behavior); and 3) offering psychological support to her.

Clinical course.

Problems in everyday life which occurred after discharge are shown by stages according to changes in symptomatology.

Stage I, characterized by difficulty in retaining learned information (January to April, 1997)

This difficulty was similar to that at the time of admission. He completely forgot episodes, if not recorded. He repeated the same questions to his family. He was unable to remember names and faces and sometimes puzzled strangers by talking to them as if they had been close acquaintances. He tended to fall into a rage. Though he appeared to be independent in his daily behavior and in tasks of self-care, he spent the whole day virtually without knowing what to do.

Family. Confused and frightened by his behavior, his children stayed away from him. His parents-in-law were reluctant to see him go out for fear of others seeing him and tried to make him stay home. Thus, his disorder caused family problems and hurt interpersonal relationships. His wife was cooperative with his rehabilitation and tried to understand his condition.

Memory notebook. He could record information on his activities voluntarily, if and when he was aware of the notebook. However, he was unable to record information other than the activities and schedule specified for training (e.g., telephone message). For a period immediately after discharge, he filled in blanks in the sections on daily activities with fabrications since he could not remember episodes for times designated in the notebook. Since he rapidly forgot the schedule after review, he was unable to manage his activities independently using the notebook. Support from the family was indispensable. Though he had some insight into his memory deficits, his awareness of the need for external compensatory procedures was inadequate.

Rehabilitation. Since he forgot the actual problems he faced in daily life, information on his everyday memory was collected from his wife through interviews. His wife provided him with check lists for the tasks that he

repeatedly asked his family if he had performed and provided him with a map when he took a walk.

Stage II, loss of continuity of memory (May to July, 1997)

Symptoms. He experienced a marked loss of continuity of memory because the retention of learned information was slightly prolonged, while episodic memory remained impaired and intermittent. He was often at a loss, being unable to recall what he had done and what to do next. Though he could recall an episode, when some cues were given, he tended to confuse what he had done with what others did. He felt much anxiety, as he was not confident of his own behavior. The tendency toward anger and rage decreased. The awareness of memory impairment improved and he became able to describe his inner life by saying, e.g., "Things are going well, while I keep walking. Once I stop, I'll be lost as to where I should go, right or left, in the world of memory."

Family. There was an improvement in interpersonal relationships in the family since he was able to take care of children and work with his mother-in-law in the field.

Memory notebook. He developed the habit of routinely taking notes of meaningful information, including telephone messages, other than his daily activities. However, he sometimes tried to write lengthy notes in the limited blanks in the book. He did not consistently carry the notebook because his mother-in-law did not like a waist pouch or for other reasons, such as avoiding getting the notebook dirty in the fields. Instead, he frequently used a memo pad, which he often lost or forgot to review. He often forgot what he read in the memo pad within a short time. Thus, prompts were necessary for him to get things done as scheduled.

Rehabilitation. The inconvenience of using a memo pad was discussed with him. He was instructed to carry the memory notebook always and to write all necessary information and priority events in it after modification was made in the format and blanks.

Stage III, paramnesia and confused sequence of events (August 1997 to September 1998)

Symptoms. His ability to recall impressive episodes without looking in the notebook occurred with increasing frequency. However, he confused what he had completed with what he should do (paramnesia) or confused events in the previous day with those in the morning of the same day (confused sequence of events). Thus, the content of his recall might need correction, depending upon confirmation by consulting the notebook or by his family. Often, he could not start necessary activities without being prompted even when he knew what he had planned to do. He complained that part of his memory sometimes would come back independently of his intention and interfere with what he was doing.

Family. Although his family members were able to understand the nature of his memory deficits, they were often irritated in daily life by the need for constant repetition of explanations and the delayed start of his subsequent behavior. He himself was aware of the frustration of his family.

Memory notebook. He was able to make frequent entries and refer to the notebook and developed a pattern of behavior to compensate for his memory impairment.

Rehabilitation. He was provided feedback of the improvement in memory disturbance and was instructed to be independent with management of activities at the hospital (e.g., checking into the outpatient service, going to the correct room at the rehabilitation outpatient clinic, paying the fee), and to start to practice coming to the hospital by himself. Assessment by the questionnaire of Sunderland *et al.* (1983) [19] in September revealed a score of 75/140 for the patient and 74/140 for the wife, showing good agreement between the two and their favorable understanding of the disorder. He gradually outgrew the need to depend on the family and led a more positive, independent life, trying a wider range of activities by the use of external memory aids. He started coming to the hospital alone as an outpatient by using the notebook and a map drawn by

his wife in January, 1998.

IV. Neuropsychological test results.

Changes in neuropsychological test scores are indicated in Table 1. His attention, frontal lobe functions and intellectual functions had virtually recovered by the time of discharge. Improvement occurred in recall, though still severely impaired, as well as in non-verbal and verbal memory. Marked improvement was noted, especially on the item of pairs of unrelated words of the Miyake Verbal Retention Test conducted in August 1996 and later.

V. Findings from brain imaging

MR scan in October 1996 demonstrated that the bilateral areas of increased signal intensity in the hippocampus were less distinct than the baseline. SPECT in November 1996 showed signs of improvement in the inflammation, though it depicted a radioisotope accumulation in the right temporal lobe (Fig. 1).

DISCUSSION

1. Amnesia due to bilateral lesions of the medial temporal lobes

It is well-documented that bilateral lesions of the medial temporal lobes result in a severe deficit of episodic memory including both anterograde and retrograde amnesia [16] while sparing procedural memory and general intelligence [13]. Amnesia due to bilateral medial temporal lobe lesions first was reported by Scoville (1954) [18], whose patient had undergone bilateral medial temporal lobe resection because of intractable epilepsy. Herpes simplex encephalitis [5] and paraneoplastic limbic encephalitis [7] are important current causes of bilateral damage to the medial temporal lobes resulting in persistent amnesia; we found no evidence for either diagnosis in our patient with bilateral temporal lobe lesions.

The long-term natural history of amnesic patients with bilateral lesions in the medial temporal lobes due to temporal lobectomy, herpes simplex encephalitis, or paraneoplastic limbic encephalitis has been described in a few case reports [1, 6, 13]. Little has been reported, however, concerning the long-term course of everyday memory and home-based rehabilitation of this memory function involving participation of family members.

In a search using the Medline database covering the period from 1966 to August 2000, we could not find a previous report describing rehabilitation based on long-term use of a memory notebook by a patient with amnesia due to bilateral medial temporal lesions.

2. Assessment

The rehabilitation program was prepared in consideration of the results of behavioral observation and self-report as well as neuropsychological assessment. Neuropsychological test batteries offered an overall profile of cognitive disorders and repeated testing allowed the tracking of improvement of symptoms. However, they did not provide information about the influence of memory failure on the everyday life of the patient and were of limited utility for defining training or its goal.

Behavioral observation of the patient in hospital was useful for setting goals in training and for assessing its effectiveness because it provided concrete information on the actual problems in daily life. Since it was not possible to get firsthand information about his behavior at home after discharge, behavioral assessment was made through interviews and self-reporting with questionnaires. Because the patient had developed insights into his disorder in hospital, it was possible to promote his accurate awareness of memory impairment by assisting him in making adjustments to his deficits and providing him feedback. Interviews allowed rehabilitation staff to gain access to valuable information on the inner life of the patient and facilitated their understanding of him. This, in consequence, seemed to promote the psychological stability of the patient. Thus, comprehensive assessment appears to be useful in devising the optimal method for helping amnesic patients.

3. Impairment in everyday memory

The patient's impairment in everyday memory had two aspects throughout the course of the disorder: 1) impaired episodic (reflective) memory, being unable to recall what he had done, and 2) impaired prospective memory, being unable to figure out what to do. Prospective memory relies on some of the same structures as episodic memory, and is impaired in the patients with episodic memory deficit [2].

Impairment in episodic memory could be compensated for relatively easily by writing his activities in the memory notebook. As the decision about priority events/experiences or which points should be recorded was left to the discretion of the patient, it was necessary for him to be aware of the extent of his forgetfulness and what kind of information he tended to forget and to select meaningful information accordingly. Since any record cannot cover details of all activities, the sense of interrupted continuity of memory could occur often or intensify with increasing severity of impairment in episodic memory.

On the other hand, it was difficult to compensate for the impairment in prospective memory. By its own nature, what can be recorded in a notebook consists mainly of information on what should be done; it is difficult to write in advance when and how various actions should be taken at the proper moment with flexibility. Thus, the notebook will not provide positive, practical instructions to compensate adequately for this impairment. Planning of future actions requires both retrieval of learned information stored in long-term memory and a simulation in the mind using working memory [8], therefore, this function may be affected more deeply than others by memory impairment.

Although his episodic memory improved gradually, the disturbance in prospective memory did not show improvement, which was responsible for his difficulty in planning and starting actions, causing anxiety and significant problems in daily life.

4. Rehabilitation of memory disorder

In this patient, the influence of amnesia was observed in various aspects of everyday life after discharge. Psychologically, emotional disturbances such as anxiety and the tendency toward rage were noted, which appeared to be attributable to limbic dysfunction and were potentiated by the secondary effect of amnesia. Interpersonal relationships were impaired, making him passive and isolated; he was unable to interact with acquaintances on equal terms, while his condition caused trouble in family life. From a behavioral aspect, he had difficulty in planning his activities. Thus, a rehabilitation program for amnesic patients should take into account not only memory impair-

ment per se but also consequent problems in daily life.

Because effectiveness of internal strategies on everyday memory impairments has not been accepted, we chose an external memory device and environmental adjustments to manage the patient's memory disorder. Preservation of general intelligence and procedural memory favored use of a memory notebook. Active participation by the patient's wife in rehabilitation during the hospital stay educated her as to how to adjust the environment and how the memory notebook would best serve him in everyday life. This experience provided her with useful information that allowed her to take better care of her husband's memory problem after discharge. Interviews and counseling enhanced her understanding of the impairment. This knowledge allowed her to modify the patient's environment and to support his activities in a way that impressed the rehabilitation staff. Since it is difficult for a hospital to provide individualized training to meet the specific needs of each patient in all spheres of activity, the burden falls on family members to work collaboratively to develop practical solutions for specific problems. Thus, we strongly believe that appropriate environmental modifications and use of an effective external memory device can improve the quality of life of patients with some type of memory impairment. However, the success of this therapeutic strategy requires a collaborative effort between the clinician and the patient's family and caregivers. This effort is most likely to be effective when clinicians take the time to explain the nature of the impairment to the family so they will be able to make informed decisions as to how best support the patient.

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