

*Original Article***Validity of the progress notebook in supporting patients with higher cortical dysfunction**

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ABSTRACT

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Purpose: To validate the usefulness of a progress notebook (p-notebook) in supporting patients with higher cortical dysfunction by analyzing the difference in interview time in a new hospital or facility with and without the p-notebook. The p-notebook was created to assist those with higher cortical dysfunction, which is not well understood by non-experts.

Methods: Interview times with and without the p-notebook (notebook group: $n=34$, non-notebook group: $n=32$) were compared when patients with higher cortical dysfunction went to a new hospital or facility. Impressions of the families and support coordinators of patients in the notebook group were evaluated using visual analogue scales.

Results: The average interview time was 32.4 ± 10.7 minutes in the notebook group and 57.2 ± 28.9 minutes in the non-notebook group, and this difference was significant ($p < 0.0001$). Regarding the impressions of family and support coordinators, the length of explanation was shorter and understandability was improved when using the p-notebook. These tendencies were dominant in families compared with support coordinators.

Conclusion: Our p-notebook is useful since it decreases the interview time and lowers the burden of giving

explanations.

Key words: higher cortical dysfunction, traumatic brain injury, cerebrovascular disorders, compensatory methods, notebook

Introduction

The term “higher cortical dysfunction” has been applied to symptoms such as aphasia, agnosia or apraxia. However, memory disturbance, inattention, executive dysfunction, and social or behavioral disturbance have been listed as principal symptoms of higher cortical dysfunction in the Model Project of Higher Cortical Dysfunction since 2001 [1]. Thereafter, only patients with those symptoms were treated as having higher cortical dysfunction under government services such as the medical insurance system, medical insurance fee system or national pension system. Since non-expert medical staff frequently do not well understand the manifestations of higher cortical dysfunction such as memory disturbance or inattention [2], patients or family members sometimes feel that it is difficult or inconvenient to describe their symptoms when they go to a new hospital or facility, which may cause problems for medical practitioners. Some patients use a notebook to assist in memory or caregivers prepare a checklist as a method to record the degree and presence of symptoms of higher cortical dysfunction [3–5], and these can be used to communicate with the facilities used by the patient. However, the usefulness of a notebook or checklist is rarely verified because of the lack of an adequate statistical method for this purpose.

We created the progress notebook to support patients with higher cortical dysfunction (p-notebook) when they must go to a new hospital or facility. We report on its validity by describing the difference in interview time with and without the p-notebook.

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Methods

1. Subjects

The subjects were 66 patients with higher cortical dysfunction whose condition required consultation with support coordinators, who assist with various issues related to their condition. After explaining the aims and usage of the p-notebook to the patients and families as well as the purposes of this study, the patients were divided into 2 groups: those who used the p-notebook in an actual interview (notebook group, 34 patients) and those who underwent a conventional interview without the p-notebook (non-notebook group, 32 patients). Causes of higher cortical dysfunction in the participants are shown in Table 1.

2. Progress notebook (p-notebook)

The p-notebook was prepared in 2 different sizes, either A6 or B6 paper. Table 2 shows the content of the p-notebook. The situation at onset of higher cortical dysfunction or the injury causing it, history of life before onset, and treatment history after onset (Fig. 1) are recorded as written descriptions. Symptoms such as memory disturbance are identified by check marks after a short phrase such as “Impossible to remember new things” (Fig. 2). To assist the support coordinator in preparing a disability pension form, there is a page with information relevant to the support or system utilization status (Fig. 3). There is also a summary of the patient’s characteristics and past history. Thus, our aim was for the p-notebook to cover almost all relevant

Table 1. Causes of higher cortical dysfunction.

	Notebook group	Non-notebook group
Traumatic brain injury	24	17
Cerebrovascular disorders	9	12
Other diseases	1	3
	34	32

Table 2. Contents of progress notebook used to support patients with higher cortical dysfunction (p-notebook).

What is higher cortical dysfunction?
Treatment at onset
Treatment history since onset
Course of symptoms from onset to 1.5 years since onset
Course of symptoms after 1.5 years since onset
Past history
Physical disability certificate and pension status
Record of support
Characteristics
Memorandum
Questions and answers
List of support organizations

Treatment history since onset	
Hospital name	/ / - / /
Period of treatment	/ / - / /
Treatment situation	
Hospital name	/ / - / /
Period of treatment	/ / - / /
Treatment situation	
Hospital name	/ / - / /
Period of treatment	/ / - / /
Treatment situation	

Figure 1. Treatment history page of the p-notebook.

Symptoms of higher cortical dysfunction (Place check.)	
Reporter's name:	
Date of observation	/ /
<input type="checkbox"/> Memory disturbance	
<input type="checkbox"/> Impossible to remember new things	
<input type="checkbox"/> Does not retain memory	
<input type="checkbox"/> Others	

<input type="checkbox"/> Inattention	
<input type="checkbox"/> Absent-minded	
<input type="checkbox"/> Lack of concentration	
<input type="checkbox"/> Others	

<input type="checkbox"/> Dysexecutive syndrome	
<input type="checkbox"/> Impossible to plan and execute something	
<input type="checkbox"/> Inefficient performance of work	
<input type="checkbox"/> Others	

<input type="checkbox"/> Social or behavioral disturbance	
<input type="checkbox"/> Verbal abuse or violence	
<input type="checkbox"/> Obsessiveness or inflexibility	
<input type="checkbox"/> Strong dependence	
<input type="checkbox"/> Others	

Figure 2. Symptom page in the p-notebook.

Physical disability certificate and pension status	
Physical disability certificate <input type="checkbox"/> Yes (Class:) <input type="checkbox"/> No	Date started / /
Remarks (e.g. Kind of disability)	
Mental disability certificate <input type="checkbox"/> Yes (Class:) <input type="checkbox"/> No	Date started / /
Remarks	
Rehabilitation certificate of disabled children	
<input type="checkbox"/> Yes () <input type="checkbox"/> No	Date started / /
Remarks	
Disability pension <input type="checkbox"/> Yes <input type="checkbox"/> No	Date started / /
Remarks (e.g. Kind)	
Act for supporting the independence of persons with disabilities	
<input type="checkbox"/> Yes <input type="checkbox"/> No	Date started / /
Remarks (e.g. Classification)	
Long-term care insurance <input type="checkbox"/> Yes <input type="checkbox"/> No	Date started / /
Remarks (e.g. Degree of care)	

Figure 3. Physical disability certificate and pension status page in the p-notebook.

information on the patient.

3. Procedure

Patients and their families in the notebook group chose the size of notebook to be used, then worked with the support collaborators to fill in all items of the p-notebook. When patients went to a new hospital or facility, their support coordinator (or sometimes the family) used the p-notebook when introducing the patient to the new staff. The interview time at the new hospital or facility was measured in both the notebook group and non-notebook group. In most cases the patient’s support coordinator measured the interview time, but if the coordinator was not present or for other reasons, the patient’s family or the institution’s case worker measured the interview time. A *t*-test was used to compare the average interview time between the two groups. Impressions at the interview were also evaluated using visual analogue scales in relation to the length of explanation and understandability of the information in the notebook group in comparison with hypothetical interviews without using the notebook. The length of explanation was rated as 0 for very short, 5 for not different, and 10 for very long and understandability was scored as 0 for very easy, 5 for not different, and 10 for very difficult. The paired *t*-test was applied to 11 pairs of impressions that were obtained from the support coordinators and family members.

Table 3. Impressions at interview.

	Family	Support coordinator
Length of explanation	2.18	3.45
standard deviation	1.99	1.86
Understandability	2.09	3.36
standard deviation	2.17	1.43

Length of explanation:

0, very short; 5, not different; 10, very long.

Understandability:

0, very easy; 5, not different; 10, very difficult.

Results

The average interview time was 32.4 ± 10.7 minutes in the notebook group and 57.2 ± 28.9 minutes in the non-notebook group, a significant difference ($p < 0.0001$). Impressions at the interview are shown in Table 3. The length of the explanation was considered to be shorter and understandability better in comparing the hypothetical interview situation with the actual interview with the p-notebook according to the visual analogue scales. Families thought that the explanation was significantly shorter than did support coordinators ($p = 0.036$) and families tended to find the information easier to understand than did support coordinators ($p = 0.072$).

Discussion

This study found that using the p-notebook significantly decreased the length of interviews when patients with higher cortical dysfunction went to a new hospital or facility, and the opinions of families and support coordinators agreed with this finding.

The Support Center for Higher Cortical Dysfunction in Fukui Prefecture [4] and the Ibarakikenritsu Rehabilitation Center [5] use checklists to help the public understand the symptoms of higher cortical dysfunction. These lists can also be used as a record of patient’s symptoms. In addition, they are useful in screening for higher cortical dysfunction. We found that it is easy for non-expert medical staff to understand the information from the beginning of creating our p-notebook. We gave extra consideration to items that would be useful when applying for a disability pension such as educational history, medical history, date of onset, or symptoms of higher cortical dysfunction.

The finding that families have a better impression of the p-notebook than support coordinators indicates that the closer to patients people are, the greater their impressions of improvements in both interview time and understandability. In other words, using the p-notebook effectively reduces the burden of care. Since the behavior of patients with higher cortical dysfunction is often thought to be mischievous by people who do not understand the symptoms of this

disorder, the burden of care is great for families.

Evidence of the effectiveness of rehabilitation for higher cortical dysfunction has been increasingly accumulated [6]. Although improvement in the cognitive dysfunction itself such as memory disturbance has occasionally been reported [7], improved elements have been the result of exercises in meta-cognition strategy for executive dysfunction or external compensation of activities [6]. However, in summary, compensation strategies such as a memory notebook are crucial. Although our study did not address the abilities of individual patients, our study's approach of using the time required for interviews would be helpful to show the usefulness of compensatory methods for higher cortical dysfunction.

One limitation of this research is that the two groups were not randomly allocated. Since we eagerly used the p-notebook just after its completion, those patients who had an opportunity to visit a new hospital were the first to be introduced to the p-notebook and to be included in the notebook group. However, we considered there was no intentional allocation of patients to one particular group, but it is possible that patients who would never have had the opportunity to utilize the p-notebook were included in the non-notebook group. The support coordinators who participated in this study were considered sufficiently experienced; nevertheless, there may have been a bias due to differences in the experience of the coordinators. Since a baseline for a short interview was not clarified in the questions using the visual analogue scale, different interpretations may have resulted. Similarly, the meaning of understandability in the visual analogue scale might be wrongly thought of as reflecting the communication skills of the support coordinators instead of the ease in transferring information.

We did not examine the patterns of higher cortical dysfunction in this study. In a future study, we will examine for which types of higher cortical dysfunction this p-notebook is more effective. In addition,

evaluation using the visual analogue scale should be conducted in all patients, including the non-notebook group.

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