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Behavioral Assessment List for Children with Acquired Brain Injury with Cognitive Dysfunction

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Abstract

Introduction: Cognitive dysfunction is a common symptom of acquired brain injury (ABI) in children and can have a significant effect on the patient's activities of daily living (ADLs) and school life. Observing the everyday and school life states of such a patient accurately and briefly can be very helpful in providing better therapy and education. ADLs and school life are affected by cognitive dysfunction; therefore, it is possible to understand the condition of a patient by observing his or her everyday behavior. In this study, we attempted to construct a behavioral assessment list for children after ABI to assess the clinical characteristics of children with cognitive dysfunction by observing their performance in ADLs and school life.

Methods: Twenty parents having children with cognitive dysfunction after acquired brain injury, 20 educators, and 20 registered occupational therapists were asked to write down the characteristic behaviors of the children in ADLs and school life. Forty occupational therapists classified them into 10 categories. An inter-item distance matrix of the characteristic behaviors was developed by the categorization method and classified by cluster analysis.

Results: The behavioral characteristics identified 225 items in ADLs and school life. The cluster analysis revealed 16 clusters, labeled as: (1) memory, (2) and (3) emotional control, (4) planning, (5) behavioral regulation, (6) monitoring, (7) awareness, (8) arousal/fatigue, (9) decision-making, (10) preservation, (11) visual perception, (12) working memory, (13) shift, (14) circle of friends, (15) speed of processing and (16) communication ability. Based on the classification of cluster analysis, 2 - 3 items for each group were extracted, and the behavioral assessment list was created that consisted of 45 items in 16 groups for children with ABIs.

Conclusion: A behavior assessment list (BAL) for children with ABI was constructed and can be used to easily assess the everyday conditions of any child with ABI and, along with other medical and neuropsychological tests, could provide better therapy for these children. However, the work of this study is still at an early stage, and it is necessary to increase the number of cases and scrutinize the outcome carefully to attain a more sophisticated BAL.

Keywords: *Acquired Brain Injury; Cognitive Dysfunction; Behavioral Assessment; ADL; Children*

Abbreviations

ABI: Acquired Brain Injury; ADLs: Activities of Daily Living; FIM: Functional Independence Measure; OTR: Registered Occupational Therapist; BAL-C: Behavioral Assessment List for Children

Introduction

Acquired brain injury (ABI) in children includes injury from various causes such as traumatic brain injury (TBI), stroke, cerebral abscess, bacterial meningitis, and neurosurgical operations [1]. ABI is a leading cause of death and lifelong disability [2]. Impairment in physical and cognitive function, emotion, and social skills, as well as personality changes are common after ABI [3]. In particular, cognitive impairment and personality changes have been shown to be closely associated with the impact on a child's daily functioning within the home, school, social adaptation, and community [4,5].

Children who survive the injury may have cognitive deficits including: vigilance attention, working memory, spatial awareness, processing speed, executive function, and self-monitoring [6,7]. These deficiencies, even if slight, can affect the child's ability to interact with the environment in the developmental process, which can lead to a delay in acquiring age-appropriate skills and potentially increasing the gap between the injured child's ability and the non-injured classmates' ability [8].

Notably, these deficits become apparent when the demands for complex human relationships and complex tasks increase in the school environment, which can lead to secondary disorders such as a delay in educational progress and deterioration of friendships [8,9].

As part of an evaluation of cognitive function after ABI in children, age-appropriate neuropsychological tests are most often performed [10]. They are used to identify specific deficits in cognitive abilities which is useful for evaluating the type and extent of disability of the body structure and function [11-13].

However, most neuropsychological studies cannot sufficiently evaluate the influence of cognitive dysfunction on everyday skills of patients with childhood ABIs [14,15]. Moreover, the current knowledge about the ecological validity of neuropsychological measures is mostly the result of studies investigating the adult and elderly population and has not been fully investigated in children [12].

Everyday activities of daily living (ADLs) and social participation (e.g., school life, friend relationships, teacher relationships) require the coordinated operation of motor systems, multiple sensory systems, cognitive systems, emotional self-regulation, motivation, and social cognition in real-world tasks [16]. The present study focuses on these aspects in children with cognitive dysfunction post-ABI.

In addition to neuropsychological tests, some studies drawing on ecological measures recommend that families, caregivers, or schoolteachers observe and evaluate ADLs and the social participation of children with ABIs [11,12,15].

There are several tests that can evaluate the influence of cognitive dysfunctions in patients' daily lives, such as the Behavior Rating Inventory of Executive Function (BRIEF) [17], the Children's Cooking Task (CCT) [18, 19], the "Birthday Task" [20] for executive function and self-regulation, the Rivermead Behavioural Memory Test for Children (RBMT-C) [21] and the Test of Everyday Attention for Children (TEA-Ch) [22] for attention. However, these kinds of tests are limited in number [10] and most questionnaires and behavioral assessment tools measure only one or a restricted aspect of functions such as executive function and memory, etc.

The purposes of this study are to (i) clarify the ways in which these deficits will affect a child's everyday functioning and to (ii) construct a behavioral assessment list for children (BAL-C) that is useful especially for non-professional caregivers, school teachers, and medical staff in order to effectively assess the performance of ADLs, school life, and other behaviors of children with ABIs. A BAL-C should consist of the statements describing everyday behaviors of children with ABIs that are easily observable by anyone who takes care of the child and the range of the behaviors to be observed must include as many relevant cognitive functions as possible.

The benefits of a BAL-C are straightforward and will be useful for rehabilitation planning and more appropriate caretaking during the entire period of the child's recovery. The present study is the first step towards this purpose and the proposal of the very first version of the BAL-C.

Materials and Methods

Subjects

This study included 20 parents who have children with ABIs, 20 schoolteachers and 60 OTRs (registered occupational therapists). The schoolteachers and OTRs have more than 5 years of experience each.

Procedures

Subjects were asked to write down characteristic behaviors that they have observed in children with ABI through ADLs and school life such as during rehabilitation training and while the children were or were not engaging in ADLs and classes in their home and school. The ADLs and school activity were described based on each of the categories of FIM (functional independence measure); eating, grooming, bathing, dressing, toileting, bladder management, bowel management, transfer, walk, wheelchair, stairs, communication (comprehension, expression), social cognition (social interaction, problem solving), memory, and others. The children's information as to the cause of their ABI and the year of injury were obtained from patients.

The characteristic behavior items, which were extracted through the above procedure, were classified according to the similarity of the presumed causes of the behavior specified by each sentence into 10 arbitrary categories by 40 of the OTRs.

Statistical analyses

Inter-item coincidence ratios of each two of the behavioral characteristic items were calculated from the frequency of which any two items were classified into the same category by the 40 OTRs. The results were analyzed by hierarchical cluster analysis (Ward's method). SPSS Statistics software (ver. 20; IBM Corp., Armonk, NY USA) was used for all analyses.

This study was performed in accordance with the Ethics Committee of Kyorin University and all patients provided informed consent.

Results and Discussion

The effect of cognitive impairment on ADLs and school life after ABI

Twenty parents who have children with ABIs, 20 schoolteachers, and 20 OTRs gave 225 sentence items through the ADLs and school life of ABI children with ABIs. Among those, 43 sentences were selected by the judges (the author, three OTRs, and a clinical psychologist) as expressing similar behavior and were thus discarded. As a result, 179 items were extracted as follows: eating, 7 items; grooming, 11 items; bathing, 12 items; dressing, 11 items; toileting, 6 items; transfer, 1 item; walk, 9 items; communication, 33 items; social cognition, 27 items; memory, 17 items; emotional control, 12 items; during class, 14 items; and homework, 11 items.

Scene of ADL and School Life	Items (Excerpt)	Number of Items (%)	
Eating	Unable to adjust the amount of bite	9	(5)
	Strong preference for likes and dislikes		
	Unable to eat according to social manners		
	Difficult to know what to do in tidying up and preparation		
Grooming	Unable to start movement of dressing without others help	11	(6)
	Difficult to shave beard without spot		
	Difficult to comb hair		
	Behaviors are rough in general		
Dressing	Unable to start movement of dressing without others help	11	(6)
	Difficult to choose clothes that match the climate		
	Difficult to get rid of the clothes you took off		
	Difficult to estimate the time needed to finish changing clothes		
Toileting	Difficult to notice dirt around the toilet	7	(4)
	Stick to the procedure		
	Difficult to take notice the dirt of floor while changing clothes etc.		

Bathing	Difficult to wash properly (some parts left dirty)	12	(7)
	Need more time for each process		
	Difficult to notice left bubbles of body		
	Stick to the procedure (e.g. washing from anywhere in the body)		
Transfer	Tend to move or behave slowly	1	(1)
Walk	Difficult to pay attention my surroundings	9	(5)
	Get tired easily		
	Unable to understand the direction while walking		
Communication	Emotional expression is poor	33	(18)
	Difficult to understand the contents of the story		
	Speak inappropriately to the context or the circumstance		
	Tends to take time to understand the content of the conversation		
	Unable to understand complicated indicating		
	Repeat the same story many times		
Social Interaction	Difficult to make friends of the same generation	27	(15)
	Unable to interact with friends using social networking sites		
	Unable to talk to someone without others help		
	Unable to keep up with the pace of conversation in a group		
Problem Solving	Difficult to estimate the time needed to finish a task (e.g. changing clothes or using the toilet)	6	(3)
	Difficult to decide what to do first		
	Difficult to follow the advices given about the order of motions in changing clothes etc.		
Working Memory	Forget having to do homework	17	(9)
	Difficult to correct what was stored wrongly		
	Tend to forget something		
	Repeat asking the same questions		
Emotional Control	Difficult to control emotions	14	(8)
	Suddenly cry		
	Tend to be irritated by trivial things		
During Class	Difficult to spend class time without sleeping	14	(8)
	Difficult to learn the class contents		
	Tend to be slow the motion at reading and writing		
	Unable to move the classroom and check the timetable without other help of the teachers and classmates		
	Having the gap between when they can do and what they can't do		
Homework	Difficult to follow the advices given about poor handwriting in a task.	11	(6)
	Tend to forget own homework		
	Unable to start homework without other help		
	Cannot make a schedule to do a homework		
	Difficult to estimate the time needed to finish a task		
Total		182	(100)

Table 1: *Specific behaviors of children with acquired brain injuries in activities of daily living and school life.*

The construction of a behavioral assessment list for children (BAL-C) after ABI

The cluster analysis

The 179 items were analyzed using hierarchical cluster analysis (Ward's method). The list was first divided into two groups and classified as 3, 4, 6, 8, 10, 16, 40 (Figure 1). We adopted 16 groups from the convergence of meaning (Table 2). The 179 items in 16 groups were labeled and interpreted as follows:

- **Cluster 1: Memory:** This cluster consisted of 20 items such as "Difficult to remember the contents of the class," "Forget to having to do homework," and "Difficult to correct what was stored wrongly" which had high factor loading. This is related to memory function such as the short-term storage, monitoring, and manipulation of information, etc [23].

- **Cluster 2 and 3: Emotional Control:** Cluster 2 included 11 items related to easy stimulability, quick temper, and mood swing [24], such as "Tend to get excited by small things," "Difficult to get back to normal when getting excited," and "Having erratically emotional ups and downs". On the other hand, cluster 3 consisted of 13 items related to anxiety and a decline in apathy and initiation [25,26], such as "Reduced emotional expression," "Tend to think to the worse," and "Difficult to go to school alone because of strongly anxiety".

- **Cluster 4: Planning:** This cluster consisted of 7 items, such as "Cannot make a schedule to do a task," "Begin something without deciding the order of doing it beforehand," and "Difficult to decide what to do first (e.g. in changing clothes and washing own body)". These items are related to planning and effective performance [27,28] and may reflect prefrontal cortex damage [29].

- **Cluster 5: Behavioral Regulation:** This cluster included 7 items related to inhibition such as overcoming strong habitual response and inhibit response [30,31]; "Tend to stuff food in own mouth one after another (even though they haven't swallowed the previous one)," "Difficult to choose clothes according to the temperature (whether it is hot or cold)," and "Unable to eat with good manners".

- **Cluster 6: Monitoring:** This cluster included 9 items and indicates an impairment in metacognition, the perspective of another and self-monitoring [32]; "Difficult to be careful about your appearance" and "Cannot realize one's own mistakes while doing something (e.g. changing clothes or using the toilet)". They may reflect polar region (10s and 10i) impairment [33].

- **Cluster 7: Awareness:** This cluster consisted of 7 items associated with the control of attention [34]; "Difficult to notice the surrounding environment (steps, walls, etc.)," "Unable to pay attention to what is in own pocket or bag".

- **Cluster 8: Arousal/Fatigue:** This cluster included 10 items, e.g., "Difficult to spend class time without sleeping," "Unable to sustain or maintain focus to complete task," and "Get tired easily". These items seem to be related to problems with concentration [35] and fatigue, which students with ABIs can experience in the post-acute recovery phase [36].

- **Cluster 9: Decision-Making:** This cluster consisted of 27 items, including "Difficult to estimate the time needed to finish a task (e.g. changing clothes or using the toilet)," "Difficult to understand the situation," and "Cannot decide the priority of the tasks to be done". These items are related to decision-making and inflexibility [37] and may reflect ventromedial frontal cortex [38] and orbitofrontal damage [39].

- **Cluster 10: Preservation:** This cluster included 4 items, e.g., "Unable to stop movement of eating or wearing," "Keep washing the same place only while cleansing or bathing," and "Repeat the same story many times". These items seem to be related to preservation [40], i.e., the tendency to not be able to inhibit the once activated behavior. It appears to affect control of attention [30], which makes it difficult to switch attention.

- **Cluster 11: Visual Perception:** This cluster included 8 items related to visual function such as neglect, visual field deficit, visual perceptual problems [41], etc.; "Difficult to copy from the blackboard," "Difficult to find their own shoebox or locker," and "Tend to hit when walking in narrow places". These items may be related to the right dorsolateral prefrontal cortex [42] and the integrity of the posterior visual pathway and cortical networks emanating from the occipital lobe [43].

- **Cluster 12: Working Memory:** This cluster consisted of 12 items, e.g., "Difficult to do two things at the same time," "Difficult to build up learning," and "Unable to remember what don't interested things". These items seem to relate to working memory, interference control, inhibition, and attentional control [44,45].

- **Cluster 13: Shift:** This cluster consisted of 7 items, e.g.," Stick to the procedure (e.g. washing from anywhere in the body)," "Tend to upset by sudden schedule changes," and "Unable to change my mind once I think". These items seem to be related to suppressing and switching [32].

- **Cluster 14: Circle of Friends:** This cluster included 14 items associated with loss of friends and social isolation [9, 46]; "No friends around the same age," "Difficult to make new friends," and "Difficult to talk to a friend from myself".

- **Cluster 15: Speed of Processing:** This cluster included 8 items, e.g., "Need more time on assignments and homework," "Tend to be slow the motion at reading and writing," and "It takes time for changing clothes, eating, bathing, etc". The slowness of information processing is a common complaint after brain injury [47,48]. Processing speed has a major influence on cognitive performance on timed tests [9,49].

- **Cluster 16: Communication Ability:** This cluster consisted of 10 items associated with nonverbal language impairment [50], understanding humor, and sharing [32] rather than aphasia; "Speak inappropriately to the context or the circumstance," "Difficult to understand other's intention or thought," and "Unable to understand complicated conversation in group".

Cluster	Items	Number of Items
1	Memory	20
2	Emotional control (easy stimulability)	11
3	Emotional control (anxiety)	13
4	Planning	7
5	Behavioral regulation	12
6	Monitoring	9
7	Awareness	7
8	Arousal/fatigability	10
9	Decision-making	27
10	Perseveration	4
11	Visual perception	8
12	Working memory	12
13	Shift	7
14	Communication	14
15	Slowness	8
16	Initiate	10
	Total	179

Table 2: *Labels and the number of items categorized by cluster analysis: the similarity of the presumed causes of the behavior of children with ABIs specified in ADLs and school life.*
Notes: *ADL: Activities of Daily Living; ABI: Acquired Brain Injury*

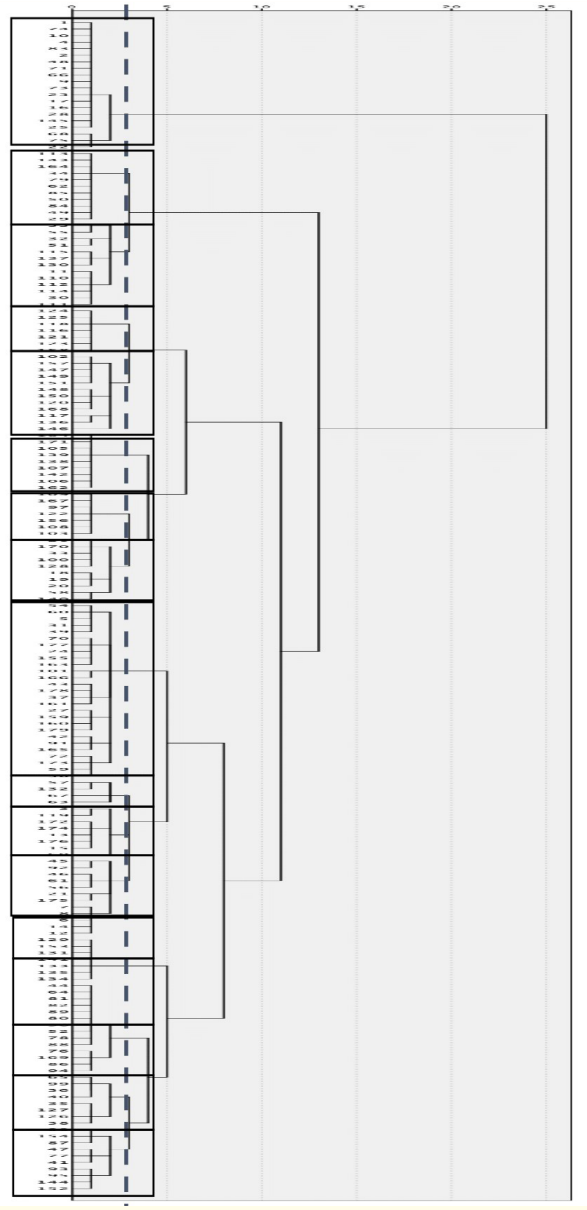

Figure 1: *The hierarchical cluster analysis (Ward's method). The list was first divided into two groups and classified as 3, 4, 6, 8, 10, 16, 40.*

The determination of the items for the behavioral assessment list for children with ABI (BAL-C): Based on the classification of the cluster analysis, we extracted 2 - 3 items for each group to balance the number in each cluster as far as possible by the criteria of clarity of meaning, plausibility of the behavior, and others by the judges mentioned above. The cluster analysis was repeated until a reasonable grouping of items was obtained by cluster analysis, based on the purpose of this study.

Finally, 45 items in 16 groups were identified as the preliminary BAL-C for children with ABIs (Table 3).

Items		Nothing admitted 0/10	Rarely admitted 1–3/10	Sometimes admitted 4–6/10	Frequently admitted 7–9/10	Always admitted 10/10	Remarks
1	Difficult to remember the contents of the class						
2	Forget having to do homework						
3	Difficult to correct what was stored wrongly						
4	Tend to get excited by small things						
5	Difficult to get back to normal when getting excited						
6	Having erratically emotional ups and downs						
7	Reduced emotional expression						
8	Tend to think to the worse						
9	Difficult to go to school alone because of strongly anxiety						
10	Cannot make a schedule to do a task						
11	Begin something without deciding the order of doing it beforehand						
12	Difficult to decide what to do first (e.g., in changing clothes and washing own body)						
13	Tend to stuff food in own mouth one after another (even though they haven't swallowed the previous one)						
14	Difficult to choose clothes according to the temperature						
15	Unable to eat with good manners						
16	Difficult to be careful about your appearance						
17	Cannot realize one's own mistakes while doing something (e.g., changing clothes or using the toilet)						
18	Difficult to notice the surrounding environment (steps, walls, etc.)						
19	Unable to pay attention to what is in own pocket or bag						
20	Difficult to spend class time without sleeping						
21	Unable to sustain or maintain focus to complete task						
22	Difficult to estimate the time needed to finish a task (e.g. changing clothes or using the toilet)						
23	Difficult to understand the situation						

24	Cannot decide the priority of the tasks to be done						
25	Unable to stop movement of eating or wearing						
26	Keep washing the same place only while cleansing or bathing						
27	Repeat the same story many times						
28	Difficult to copy from the blackboard						
29	Difficult to find their own shoebox or locker						
30	Tend to hit when walking in narrow places						
31	Difficult to do two things at the same time						
32	Difficult to build up learning						
33	Unable to remember what don't interested things						
34	Stick to the procedure (e.g., washing from anywhere in the body)						
35	Tend to upset by sudden schedule changes						
36	Unable to change my mind once I think						
37	No friends around the same age						
38	Difficult to make new friends						
39	Difficult to talk to a friend from myself						
40	Need more time on assignments and homework						
41	Tend to be slow the motion at reading and writing						
42	It takes time for changing clothes, eating, bathing, etc.						
43	Speak inappropriately to the context or the circumstance						
44	Difficult to understand other's intention or thought						
45	Unable to understand complicated conversation in group						
Total							

Table 3: *The behavioral assessment list for children with acquired brain injury (BAL-C) based on cluster analysis.*

The results from the study clarified the specific behaviors in which cognitive deficits will affect a child's everyday functioning.

The results indicate that the behaviors of children with ABIs consist of emotions such as apathy, anxiety, and depression as well as cognitive functions such as arousal, memory, working memory, attention, executive functions, communication, and perseveration. A lot of items related to executive functions such as planning, monitoring, shifting, and behavioral regulation were extracted from ADLs and

school life scenes in children with ABIs. It can be said that those aspects in children with ABIs have not been sufficiently evaluated by the existing neuropsychological tests.

In rehabilitation, the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) model is often referred to, but usually "body structure and function" in the model are considered separate from "activity and participation". There are tools to measure the type and degree of disability in the body structure and functions of the ICF, while there are few tools to measure activity and participation. Adequate tools to obtain information about activities and participation of the patients from caregivers and educators are needed since children with ABIs spend long periods of time at home and in school rather than in a hospital. Therefore, the BAL-C can serve as an adequate tool that can assess activities and participation. Above all, non-professional caregivers can evaluate children with ABIs using the BAL-C and share the information with professionals.

Study Limitations

The present study aimed to develop a scale to measure the difficulty in the performance of ADLs and school life of children with ABIs. Therefore, the items classified as characteristic behavior in ADLs and school life in children with ABIs were used to construct the BAL-C. This list is preliminary, and the reliability and validity of this list have not been examined at this stage. In the next step of the present study, it will be necessary to evaluate a number of cases in real ADLs and school settings to verify reliability and validity.

The BAL-C of the present study had 45 items. Among them are several sentences that continue to resemble each other in their meaning. Further work to refine and reduce the number of items is possible and preferable.

Conclusion

In this study, we developed a BAL-C especially designed to assess the difficulties in ADLs and school life of children with ABIs. The intended target users of this BAL-C are non-professional caregivers, schoolteachers, and experienced medical staff. By using the BAL-C, cognitive function items such as executive function, attention function, memory, working memory, communication, and preservation could be easily assessed by observing the everyday behavior of children with ABIs in any circumstance. Sharing the results of the BAL-C would bring important clues to better rehabilitation planning and help to quickly grasp the rough stage of recovery of the children.

In the next step of the present study, it will be necessary to increase the number of cases to verify reliability and validity. It may also be said that reducing the number of assessment items will be necessary to improve the BAL-C for more practical use.

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Conflict of Interest

None.

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