Nutritional evaluation of children with severe motor and intellectual disabilities

Yoshito Fujitake,1 Toshiyuki Iwasaki,1 Noriko Suyama,2 Shigeko Endo,3 Mariko Arai,4 Miwako Sasaki,5 Masae Yazawa,5 Shigeyuki Otsu,1 Masahiro Ishii1

1 Department of Pediatrics, Kitasato University School of Medicine
2 Department of Nutrition, Kitasato University Hospital
3 Department of Clinical Laboratory, Kitasato University Hospital
4 Department of Pharmacy, Kitasato University Hospital
5 Department of Nursing, Kitasato University Hospital

Objective: The present study evaluated the nutrition of 10 children with severe motor and intellectual disabilities who were hospitalized or had multiple hospitalizations and discharges over a period of more than 1 year.

Methods: The authors compared the height, weight, presence of trace elements, daily caloric intake, and the rate of change in the blood analysis parameters for the nutritional evaluation among 6 patients whose weights increased (increased group) and 4 patients whose weights decreased or showed no change (non-increased group) and investigated the nutritional characteristics of these children with severe motor and intellectual disabilities.

Results: The patients' heights and weights at the start of the observation period were lower than the ideal values (P < 0.01) because the prevention of obesity is crucial for maintaining the quality of life of children with severe motor and intellectual disabilities. Moreover, the rates of change in the daily energy showed no significant differences between the increased and non-increased groups. The rates of change in the total protein and albumin levels in the non-increased group were significantly lower than those in the increased group (P < 0.05). The levels of 5 parameters (prealbumin, total cholesterol, hemoglobin, hematocrit, and iron) were lower than normal.

Conclusions: These findings suggest that the rates of change in the total protein and albumin levels are useful for nutritional evaluation in children with severe motor and intellectual disabilities. The estimated caloric intake has to be carefully determined.

Key words: children with severe motor and intellectual disabilities, estimated caloric intake, nutritional evaluation, nutrition support team, trace elements

Introduction

Children with severe motor and intellectual disabilities are defined in Japan as those with intelligence quotients lower than 35 and a poorly maintained standing posture, or those who are bedridden.1 Cerebral palsy (CP) is a major cause of this disorder.2 All of these patients need their families' and care providers' help for their daily life activities because they cannot maintain their own posture by themselves or communicate using verbal language. These patients frequently suffer from chronic diseases, such as epilepsy, recurrent infectious diseases, and secondary osteoporosis. Furthermore, they generally have to receive enteral feeding using a nasogastric tube or a gastric fistula because of difficulties swallowing food. Many of these patients need assistance in every aspect of daily living and require time-consuming medical and nursing care.3 These patients often cannot stay at home due to the difficulties associated with their care and nursing. Therefore, they are often hospitalized for long periods.

It is difficult to evaluate the nutritional needs of these children due to the remarkable differences in their growth, development, and activity. However, it is important to estimate the relation between nutrition and growth for healthy children and patients with CP, which is associated...
with severe motor and intellectual disabilities. It has been suggested that it is especially important to pay attention to the fat ratio of children with severe motor and intellectual disabilities who have enteral feeding using a nasogastric tube rather than a simple comparison of their weight because their caloric intakes are much higher than those for healthy children. In particular, children with the spastic type of CP have been shown to have a very high energy expenditure. On the other hand, there were some reports that have described a low energy consumption for such children, and they had an excessive dietary intake with enteral feeding through a gastric fistula.

Trace elements play important roles in the maturation of brain cells and nervous tissue. The need for supplementary vitamins is often noted because bedridden children with severe motor and intellectual disabilities often develop scurvy and bone metabolic disorders; moreover, there is an elevated risk for rickets induced by antiepileptic drugs.

All the patients in the present study were diagnosed with a similar spastic type of CP, respired spontaneously, and had not suffered from any severe infections since they were hospitalized. It was not easy for them to be discharged from Kitasato University Hospital because their families could not care for or treat them at home. The study, therefore, allowed for a comparison of factors that influence nutrition due to long-term bedridden status in patients with minimal differences in activity. The study compared the height and weight of each patient, the method and type of nutrition, and presence of trace elements, daily caloric intake, and blood test results to evaluate the nutritional status of these children who required prolonged hospitalization.

Methods

Patient selection

Subjects were chosen from the population of children with severe motor and intellectual disabilities who were hospitalized in Kitasato University Hospital during the observation period, and whose severity of disabilities was classified. The subjects finally selected for inclusion in the present study were 10 children with severe motor and intellectual disabilities (5 males; 5 females; mean age, 8.8 years), who had been admitted to the pediatric department of Kitasato University Hospital from August 2008 through July 2010. The severity was classified according to the criteria defined by Suzuki et al. The selection of the subjects was assisted by the Nutrition Support Team (NST) at Kitasato University Hospital.

The causes of the children with severe motor and intellectual disabilities were CP due to asphyxia or hypoxia of the brain in 7 cases, encephalitis or encephalopathy in 2 patients, and an unidentified illness in 1 patient. All the patients presented with spastic paralysis. The reasons for their hospitalization were pneumonia or sepsis in 5 cases, and 3 patients had frequent seizures or status epilepticus, and a combination of both in 2 cases. However, none suffered any major infections after they were admitted. During the entire period of hospitalization, each of these 10 patients spent their time in bed or in a wheelchair and received physical rehabilitation of nearly the same loading of caloric consumption. All of the patients had spontaneous respiration, so none of them required a respirator.

The patients were classified into 2 groups: those who showed an increase in weight (increased group, n = 6) and those who did not (non-increased group, n = 4).

Study design

Each examination and measurement was performed a few days before discharge and 1 year before the last examination. The examination included: total protein (TP), albumin (Alb), retinol-binding protein (RBP), prealbumin (PAB), total cholesterol (T-Chol), hemoglobin (Hb), hematocrit (Ht), iron (Fe), and zinc (Zn), which are frequently evaluated in nutritional evaluations. The maximum and minimum of the general normal limits were determined according to the guidelines of the Ministry of Health, Labour and Welfare of Japan and the “BMR × 1.32” that was reported by Hogan. Both of these values were used to determine the ideal daily caloric intake for these 10 patients.

The study compared the height and weight, trace elements, daily caloric intake, and the biochemical values described above between the two groups. The rates of change were calculated as follows.

\[
\text{Rate of change} = \frac{\text{Value at discharge} - \text{Value 1 year prior}}{\text{Value 1 year prior}} \times 100
\]

The present study was performed according to the principles of the Declaration of Helsinki. The objective of the study was explained to the patients’ parents, who provided written informed consent.
**Statistical analyses**

The statistical analyses were performed using the nonparametric test, the Mann-Whitney U test between the increased and the non-increased groups, and Wilcoxon's signed rank test between the actual and ideal values to determine significant differences for the two comparisons. Excel Statistics 2010 (Social Survey Research Information, Tokyo) with Microsoft Excel software programs were used for the analyses.

**Results**

The patients' data are summarized in Table 1. All of the patients received enteral feeding and supplemental trace elements, and none of them had any problems with digestion or absorption. Five patients were fed through a nasogastric tube, and the other 5 through a gastric fistula.

The patients' heights and weights were compared with the ideal values suitable for their ages (Figure 1).

<table>
<thead>
<tr>
<th>Classification</th>
<th>Gender (yrs)</th>
<th>Tube feeding type</th>
<th>Cause of admission</th>
<th>Height (cm)</th>
<th>BW (kg)</th>
<th>CI (kcal)</th>
<th>Fe intake (mg/day)</th>
<th>Zn intake (mg/day)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>M 18</td>
<td>GF</td>
<td>Sepsis and SE</td>
<td>138</td>
<td>23.6</td>
<td>1,100</td>
<td>7</td>
<td>7.2</td>
</tr>
<tr>
<td>I</td>
<td>M 2</td>
<td>NGT</td>
<td>Sepsis</td>
<td>77</td>
<td>8.9</td>
<td>700</td>
<td>10.5</td>
<td>7</td>
</tr>
<tr>
<td>I</td>
<td>M 14</td>
<td>NGT</td>
<td>SE</td>
<td>110</td>
<td>22.9</td>
<td>450</td>
<td>3.1</td>
<td>3.3</td>
</tr>
<tr>
<td>I</td>
<td>M 14</td>
<td>GF</td>
<td>FS</td>
<td>127</td>
<td>22</td>
<td>800</td>
<td>4.8</td>
<td>4.8</td>
</tr>
<tr>
<td>I</td>
<td>F 4</td>
<td>NGT</td>
<td>Pneumonia</td>
<td>84.5</td>
<td>8.5</td>
<td>600</td>
<td>5.8</td>
<td>9.6</td>
</tr>
<tr>
<td>I</td>
<td>M 5</td>
<td>NGT</td>
<td>Pneumonia</td>
<td>109</td>
<td>19.5</td>
<td>400</td>
<td>4</td>
<td>6.6</td>
</tr>
</tbody>
</table>

BW, body weight; CI, caloric intake; FS, frequent seizures; GF, gastric fistula; I, increased group; N, non-increased group; NGT, nasogastric tube; SE, status epilepticus

**Figure 1.** Comparison between the actual and ideal values of height, weight, and daily estimated energy. The upper and lower borders of each rectangle indicate +1SD and -1SD, respectively. The horizontal bars in the rectangles indicate median values. Error bars represent maximum and minimum values. Wilcoxon's signed rank test showed significant differences between the actual and ideal values for height and weight. *P < 0.01.
Figure 2. Comparison between the increased and non-increased groups in the daily actual caloric intake. The upper and lower borders of each rectangle indicate +1SD and -1SD, respectively. The horizontal bars in the rectangles indicate median values. Error bars represent maximum and minimum values. The rate of change in the daily caloric intake was high in both groups. There were no significant differences between the groups according to the Mann-Whitney U test.

Figure 3. Blood biochemical test. The open and closed circles indicate patients in the increased and non-increased groups, respectively. Circles aligned on the right in each rectangle represent values examined a few days before discharge, whereas those aligned on the left represent values examined 1 year before discharge. Shaded areas indicate normal ranges. The TP, Alb, RBP, and Zn levels were within the general normal ranges; however, the PAB, T-Chol, Hb, Ht, and Fe levels were lower than the normal ranges.

TP, total protein; Alb, albumin; RBP, retinol-binding protein; PAB, prealbumin; T-Chol, total cholesterol; Hb, hemoglobin; Ht, hematocrit; Fe, iron; Zn, zinc.
Figure 4. Comparison of the rates of change in the results of the biochemical tests. The upper and lower borders of each rectangle indicate +1SD and -1SD, respectively. The horizontal bars in the rectangles indicate median values. The error bars represent maximum and minimum values. The Mann-Whitney U test demonstrated that the rates of change in the TP and Alb levels were significantly lower in the non-increased group. **P < 0.05
Wilcoxon's signed rank test revealed significant differences between the actual and ideal values \((P = 0.007)\). The patients' heights and weights were significantly lower than those of ideal values at the start of the study. However, there were no significant differences between the patients' actual daily caloric intake and their ideal intake \((\text{BMR} + \text{ER}; P = 0.721, \text{BMR} \times 1.32; P = 0.139)\). Furthermore, the rates of change in the daily caloric intake showed no statistically significant differences between the increased and non-increased groups according to the Mann-Whitney \(U\) test (Figure 2).

The blood test results examined a few days before discharge and 1 year prior were compared with the normal range (Figure 3). The subjects' TP, Alb, and RBP levels were within the general normal limits; however, the serum PAB, T-Chol, Hb, Ht, and Fe values tended to be lower than the normal ranges. No significant difference was noticed between the increased and non-increased groups or between both timepoints.

Finally, the rate of change for each parameter was compared between patients in the increased and non-increased groups using the Mann-Whitney \(U\) test (Figure 4). The rates of change of TP and Alb in the non-increased group were significantly lower with compared those in the increased group \((P = 0.011\) and \(P = 0.033\), respectively). There were dispersions of the result in the rates of change of the PAB and RBP. Moreover, their parameters including T-Chol were slightly lower in the non-increased group compared with those in the increased group but were not statistically significant. The blood cell counts and trace elements, except for Fe, showed minimal differences, and the rates of change were close to 0. The rate of change of Fe was elevated in both groups, and the rate in the non-increased group increased higher than that in the increased group, but the difference was not statistically significant.

**Discussion**

The height and weight of children with severe motor and intellectual disabilities were compared with the ideal values, and both height and weight were found to be lower than the ideal values. It is difficult to define the estimated caloric intake in children with severe motor and intellectual disabilities because it is difficult to evaluate the energy used for hypertonias, convulsions, the voluntary movements,\(^{13,14}\) and the energy expended during labored breathing, all of which are variable among patients. Therefore, there is an increased risk that inappropriate nutrition may cause chronic hypoalimentation.\(^{15}\) To avoid this risk, the nutrition support team (NST) should evaluate the patients' nutritional status and advise physicians about appropriate nutrition.

On the other hand, excessive care and nursing in childhood may be associated with obesity later in life.\(^{16,17}\) Lifestyle-related diseases, including liver dysfunction and hypertension with fatty liver, and redundant perithoracic fat, can cause labored breathing, especially in children with severe motor and intellectual disabilities. Obesity becomes a serious problem for the parents, family members, and care providers assisting these patients. The prevention of obesity is crucial for maintaining the quality of life of a child with severe motor and intellectual disabilities.\(^{18}\) Therefore, it is necessary to avoid excessive energy intake and to use the NST's suggestions.

The patients were classified into the increased and the non-increased groups, and their nutritional status were compared between the two groups. Daily caloric intake increased in both groups however, the rates of change were not statistically different between the two groups. Consequently, the caloric consumption in the non-increased group was higher than expected. Therefore, it is necessary to observe the nutritional status and growth rate of each patient frequently to re-evaluate the nutritional intake.

Insufficient intakes of vitamins and trace elements, which have been reported in patients on long-term enteral feeding, have attracted attention. Insufficient intake of vitamins and trace elements such as iodine, selenium, and Zn is associated with not only deleterious effects on the nervous system but also anemia,\(^{18}\) scurvy,\(^9\) and bone metabolism disorders\(^{10}\) such as rickets.\(^{12}\) In the present study, we found that the patients ingested the required levels of Fe and Zn, but that blood levels of Fe and Zn in many children were lower than the normal ranges.

Children in this study consumed a polymeric formula. When focused on Fe and Zn, the contents of these contained in the polymeric formula available in Japan are 0.6 mg/100 ml each. The required intake of Fe is 3.5\( - 4\) mg/day in infants and 4.5\( - 8\) mg/day in school-age children and adolescents, while that of Zn is 3\( - 5\) mg/day and 6\( - 9\) mg/day, respectively. Therefore, considering the intake of the polymeric formula, the levels of both are insufficient based on the nutritional requirements in some patients. In this occasion, supplements to provide sufficient trace elements should be considered.

The TP, Alb, and RBP levels were largely within normal ranges, but those of PAB, T-Chol, Hb, and Ht were lower than the normal ranges. On the other hand,
the rates of the changes in the TP and Alb levels were significantly lower in the non-increased group compared with those in the increased group. PAB and RBP levels are reported to indicate early nutritional status. However, based on the present study, longitudinal observation of these two factors is important and effective for the nutritional evaluation of children with severe motor and intellectual disabilities. Rates of changes in PAB and RBP were also lower in the non-increased group compared with those in the increased group, however, they were not statistically significant. Therefore, the rates of changes in the TP and Alb levels may be effective markers to assess patients’ long-term nutritional status.

In summary, nutritional evaluation of children with severe motor and intellectual disabilities is difficult due to the remarkable differences in the growth and activity of subjects during childhood. The present study demonstrated that the rates of changes in TP and Alb values were effective to determine the long-term nutritional evaluation of each patient.

Acknowledgements
The abstract of this paper was presented in part at the 14th Annual Meeting of the Japan Society of Metabolism and Clinical Nutrition in Yokohama, Japan, January 2011.

References