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Support for Children under Long-Term Medical Treatment during Transition to School

Rie Maeuma¹, Nobuko Matsuda²

Abstract

[Purpose] This study aimed at detecting, in an early stage, needs for support and investigating what is required to support children under medical treatment for a long-term and their family appropriately.

[Method] The study participants were mothers of children with congenital heart disease, type I diabetes, congenital biliary atresia, juvenile rheumatoid arthritis and occlusive disease in circle of Willis. An anonymous self-report method questionnaire was provided through mail, which included baseline characteristics, school accommodation scale, trait anxiety scale, and concerns during transition to school and consulting situation. Analysis was conducted on 145 participants.

[Results] The concerns during of the mothers children's period of transition to starting elementary school life decreased as they progressed in school, but there was an increase in their mother's primary concerns, which were related to their children's friends. The consultation received for these concerns was insufficient. A negative correlation was observed between the child's school adjustment and the mother's anxiety. The children's school adjustment was related to activities of daily life, means of commuting, period of diagnosis and enrolment in support classes. The mother's anxiety was related to time of the year, grade level, birth order and presence of long-term medical care.

[Conclusion] The results indicated the necessity for prioritizing support in school life for first-born children, children in the first grade, those who have a low level of life autonomy and those who require medical care. Insufficient consultation necessitates the need for a system providing ongoing consultation beginning from pre-enrolment and for an opportunity to obtain practical information.

Key Words

Children under medical treatment for a long time, Support content,
Period of transition to starting elementary school life,
Child's school adjustment, Mother's anxiety

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INTRODUCTION

There are over 500 illnesses, including intractable conditions, for which children require long-term care, such as endocrine disease, malignant neoplasm's and progressive neuromuscular disease. Over 200 thousand children nationwide live in long-term care¹⁾. The children who require long term medical treatment because of chronic diseases such as an intractable disease (hereafter children under medical treatment for a long time) and their families face large financial, physical and mental burden resulting from their extended care. Since their support systems are limited, they are subjected to strained circumstances²⁾. Programs for childhood chronic diseases have been established through subsidies and the Child Welfare Act since 2005, and have stabilized, but they require copayments and have narrowed down the participants by prioritizing severe cases. Moreover, in 2006, service provision began under the Services and Supports for Persons with Disabilities Act, but their support system for children was not sufficient, and an investigative commission has been established to review the services. A fact-finding survey in Wakayama Prefecture found that the most common onset period for children under medical treatment for a long time is under the age of 1 year, at 41.0%, and this increases to 65.5% if all onsets prior to attending school are included³⁾. Similarly, a 2011 report by the Health and Labor Sciences Research found that the majority of children have an onset at age 0. Furthermore, a 2006 report presented that about 90% of these school-age children with chronic diseases are enrolled in normal classes nationwide, and comprise 2–3% of all elementary and middle school children⁴⁾. Therefore, it is critical to provide rehabilitative support prior to attending school and support for school life in the community that corresponds to the child's growth and development. Support is required to allow them to understand and live with their disease and continued support to allow others around them to gain an accurate understanding of their disease. To support children under medical treatment for a long time, comprehensive services must be provided in communities including health care, medical care, welfare, childcare and educational institutions. However, the current mother and child health care activities in communities lack cooperation with school health services following school attendance. A specialist committee was established in January 2013 to review the state of support for patients of children with chronic diseases by the Ministry of Health, Labour and Welfare. Their interim report on 'The State of Support for Children with Chronic Conditions and Their Families' provides the following three

tasks and directions: 1. establishment of an impartial and stable medical fee subsidy mechanism, 2. furthering research and improving the quality of medical care and 3. promoting healthy upbringing and social participation based on the characteristics of children with chronic conditions, and fulfilment of community support for families, thus, seeking the actualization of better support in the future.

Compared with support systems for children with physical or intellectual disabilities, there has been meagre maintenance of the support system for children under medical treatment for a long time, and few studies have addressed this. Among these, a period of transition to starting elementary school life is the stage where they are enrolled in the school, and it is the decisive moment for whether they will adequately adapt to a new environment or whether this change will cause inconveniences. It is called a critical environmental transition, and this is a crucial stage for not only the children but also their mothers⁵⁾. Therefore, we wish to investigate the condition of the school life of children in long-term care with a focus on such a period of transition to starting elementary school life (hereafter a transition to attending school), and to specify the content of support within the community such children and parents live in.

There are five purposes for this study focusing upon children under medical treatment for a long time. 1) to shed light on their school lives during the transition to elementary school . 2) to make it clear what troubles they have and how they developed at the time of school attendance. 3) to reveal the factors relating to their adjustment situations of school life. 4) to identify the factors relating to anxieties of their mothers. 5) to contribute to early detection of needs for support and investigation of what is needed to support children and their family appropriately.

METHODS

1 . Pre-Study

We conducted a semi-structured individual interview for four mothers of children under medical treatment for a long time. Each of these mothers was asked about concerns and anxieties regarding entering school, improvement that occurred after receiving support, the school system and their expectations for health, welfare and medical organizations.

These results were incorporated as data and were used as the conceptual framework for this study.

2 . Participants

Patients and families with many children enrolled in regular classes from the following five organizations were invited to participate. Four hundred and seventy guardians (mainly mothers) of first- to third-grade children, who consented to cooperate, were the study participants: (1) National Association for Protecting Children with Heart Disease(250 guardians); (2) Tsubomi Association (type I diabetes,93 guardians); (3) Association for Protecting Children with Biliary Atresia(76 guardians); (4) Asunaro Association (juvenile rheumatoid arthritis, 35 guardians) and (5) Moya Association (occlusive disease in circle of Willis, 16 guardians). Four hundred and seventy guardians (mainly mothers) of grade1 (6.50-7.49 years old), grade2 (7.50-8.49 years old), and grade3 (8.50-9.49 years old) children, who consented to cooperate, were the study participants. This observation period was from June-July, 2013 .

3 . Date collection

Written requests were sent to the parents' associations introduced by the authorized Non-Profit Organization (NPO) National Support Network for Children with Intractable Diseases and patient-family associations of a national organization. Consent was obtained, and then survey sheets, requests and return envelopes were sent. We administered the self-styled questionnaire to the participants; their anonymity was ensured. The questionnaire items were constructed by the author using results from the pre-study.

We asked participants to look back over their past: they were required to regard the time of answering the questionnaire as “the present,” the time before sending the children to school as “pre-enrollment” and the period till the span of three months since the children had started school life as “post-enrollment .”

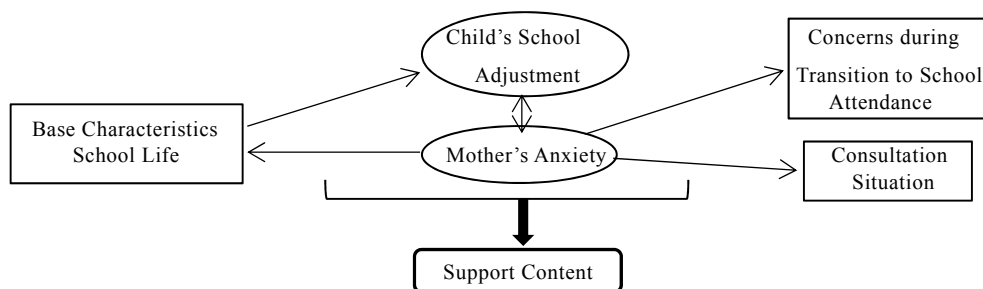


Fig.1: Research Framework

As shown in Figure 1, the survey items consisted of (1) base characteristics (the child's school life conditions, school attendance consultation, the most anxious period); (2) the child's school adjustment (self-produced school adjustment scale); (3) the mother's anxiety (STAI), (4) concerns during the transition to school attendance (before enrollment, after enrollment and present) and (5) consultation situation. Responses regarding other helpful supports or supports that will be necessary in the future were given by free description. The situation of the school life of children under medical treatment for a long time during the transition to attending school, as well as changes in worries and concerns, were identified from these survey results. Moreover, as displayed by the arrows in Fig 1, the following relationships were examined to identify the supports that would be helpful and the supports that would be necessary: the relationship between the child's school adjustment and the mother's anxiety; the relationship between base characteristics/school life conditions and the child's school adjustment; the relationship between the mother's anxiety and base characteristics/school life conditions; the relationship between the mother's anxiety and concerns during transition to school attendance and the relationship between the mother's anxiety and consultation situation.

4. Survey Contents

1) Participants' Base Characteristics, School Life

The survey enquired about the child's grade, gender, family situation, birth order, disease(s), time of diagnosis, treatment condition, presence of medical care, daily life activities, school of enrollment, class, means of commutation and consultation regarding schooling.

2) Child's School Adjustment

We constructed a scale of the original school adaptation situation in reference to the standard of Watanabe et al.'s School Avoidance Affect Measurement⁶⁾ based on the contents which we extracted from our pre-study (although, its validity or singular dimensionality as a measurement was not confirmed, hereafter the School Adjustment Scale). The School Adjustment Scale was used which consisted of ten items including contents extracted from the pre-study, enquiring about school, teachers and intimacy with friends, and evaluated on a 5-point Likert scale ranging from 0 to 4, with a higher score implying higher adjustment level. We examined reliability using factor analysis.

3) Mother's Anxiety

Using the STAI, the mothers' current feelings were evaluated using 20 items on a 4-point Likert scale ranging from 1 to 4. A higher score indicated a higher anxiety

level.

4) Concerns during Transition to School Attendance

Participants were given 10 items, which included concerns extracted in the pre-study and other items. They were asked to respond to them at three points in time: pre-enrollment, post-enrollment (up to 3 months after enrollment), and the time of the present study. Furthermore, they were asked to name the thing that worried them most for each period relating to the school life of the child.

5) Consultation Situation

For each response given to their (4) concerns during the transition to school attendance, the participants were asked who they consulted and what the results were. They gave free responses to the specific contents of handling and the support that was most helpful. As for needed support, the participants were asked to choose from ten items extracted from the piloted study, with multiple responses permitted.

5. Analysis Method

Descriptive statistical analysis was performed for each survey item.

For the school adjustment scale created by the authors, factor analysis was conducted to evaluate the reliability for each factor, and the correlation with the STAI score was examined.

The distribution of the school adjustment scale scores was examined, and the Mann–Whitney U Test and Kruskal–Wallis Test were performed for each item, with the total score as the dependent variable.

The distribution of the STAI score was examined, and based on the mean score (39.5) for women from 25 to 54 years old obtained by Nakazato et al.'s study⁷⁾. The participants were divided into the high-anxiety group (score of 40 or higher) and low anxiety group (score of 39 or lower). A chi-square test was conducted on each item with the presence of consultation and concerns during the transition to school attendance.

For the presence of each of the 10 items regarding concerns, a Holm correction was conducted to adjust for the increase in error due to multiplicity. A Pairwise Fissure Test was conducted to compare the presence or absence of worries for each question. For the primary concern for each period during the transition to school attendance, the differences between pre-enrollment, post-enrollment and the present were analyzed with a McNemar Test on the responses to the items for pre-enrollment, post-enrollment and the present. For the free description, similar opinions were aggregated and categorized.

SPSS ver.22, R-3.1.1⁸⁾ was used for statistical analysis, and 5% probability was used as the statistical significance level.

6 . Ethical Considerations

Participants were given an explanation on the main purpose of the study in writing informed they were free to participate or withdraw from the study and that returning the questionnaire meant consenting to participate in the study. They were given an explanation that the questionnaire was anonymous, personal information would be handled with care and participants would not be identified using the data for analysis based on their responses to the questionnaire. The study was reviewed and approved by Kobe University Graduate School Ethics Screening Committee prior to conducting the study.

RESULTS

One hundred and sixty-three responses (response rate: 34.7%) were obtained. There are variations in responses rates : (1) 35.6%, National Association for Protecting Children with Heart Disease, (2) 17.2%, Tsubomi Association of Type I diabetes, (3) 46.1%, Association for Protecting Children with Biliary Atresia, (4) 45.7%, Juvenile rheumatoid arthritis, (5) 17.2%, Occlusive disease in circle of Willis. Excluding participants whose grade levels were deemed uncertain or outside the target range, the results of 145 valid responses were used for analysis.

1 . Participants' Basic Characteristics, School Life Conditions, Schooling Consultation(Table1)

The most frequent grade level of participants was grade 1 (37.2%), followed by grade 2 (34.5%), and grade 3 (28.3%). 53.1% were male. The most frequent disease was Cardiac disease (congenital heart disease) 54.5%, followed by congenital biliary atresia 22.8%. The most frequent time of diagnosis was sometime after birth 52.4%, followed by at birth 42.8%. The most frequent treatment situation was observation 63.4%, followed by outpatient treatment 25.5% and required medical care 25.5%. As for the birth order, second-born was 72.4%, and first-born was 27.6%. The most common family size was 4 (40.7%), followed by 5 (23.4%) and 3 (20.0%).

Table 1: Basic Characteristics of respondents and their children (n=145)

Table 1. Basic Characteristics of Respondents and their Children (N=146)				Regarding School			
Attributes			%				%
Respondents	Mother	145	100	School	Public Elementary School	135	93.1
Grade	Grade 1	54	37.2		Private Elementary School	6	4.1
	Grade 2	50	34.5		Other	3	2.1
	Grade 3	41	28.3		Unknown	1	0.7
Gender	Boy	77	53.1	Regular Classes		119	82.1
	Girl	66	45.5	Support Classes		24	16.6
	Unknown	2	1.4		Learning	12	8.3
Disease	Cardiac Disease	79	54.5		Illness	5	3.4
	Biliary Atresia	33	22.8		Physical Disability	4	2.8
	Type I Diabetes	16	11		Affect	3	2.1
	Rheumatism	12	8.3	Unknown		2	1.4
	Moyamoya Disease	5	3.4	Means of Commuting	Walk by Self	109	75.2
					Transport by Guardian	26	17.9
Diagnostic Period	After Birth	76	52.4		School Bus	4	2.8
	Upon Birth	62	42.8		Other	5	3.4
	Before Birth	7	4.8		Unknown	1	0.7
Treatment Situation	Observation	92	63.4	Regarding School Attendance Consultation			
	Outpatient Treatment	37	25.5	Catalyst for	Self	78	55.3
	Hospitalization	6	4.1	Consultation	No Consultation	44	31.2
	No Examination	1	0.7		School/Board of Education, Etc.	19	13.5
	Other	3	2.1	Period of	1 Year to 6 Months Before Enrollment	28	28.9
	Unknown	6	4.1	Consultation	6-3 Months Before Enrollment	24	24.7
Medical Care	Absent	108	74.5		n= 97 Less than 3 Months Before Enrollment	22	22.7
	Present	37	25.5		Over 1 Year Before Enrollment	12	12.4
Birth Order	Second Child	105	72.4		1 Year Before Enrollment	10	10.3
	First Child	40	27.6	Frequency of	2-4 times	57	57.6
Family Size	4	59	40.7	School Consultation	1 time	24	24.2
	5	34	23.4		n= 99 5-10 times	13	13.1
	3	29	20.0		Over 10 times	5	5.1
	6	13	9.0	Satisfaction with	Mostly satisfied	55	53.9
	7	4	2.8	Consultation	Satisfied	38	37.3
	8	3	2.1		n=102 Somewhat dissatisfied	9	8.8
	2	1	0.7		Dissatisfied	0	0
	9	1	0.7				
Daily Life Activities							
Eating	Independent	138	95.2				
	Partially Assisted	5	3.4				
	Assisted	2	1.4				
Elimination	Independent	131	90.3				
	Partially Assisted	11	7.6				
	Assisted	3	2.1				
Communication	Independent	130	89.7				
	Partially Assisted	11	7.6				
	Assisted	4	2.8				
Movement	Independent	132	91.0				
	Partially Assisted	8	5.5				
	Assisted	5	3.4				

Nearly 90% of the participants responded as independent in every item on the daily life activities. Most of the children (over 80%) were enrolled in regular classes.

Consultation seeking for schooling was frequently observed among the mothers at 55.3%, while 31.2% did not receive consultation. For timing of consultation seeking, about 80% received it within one year of enrollment. For frequency of receiving consultation, 57.6% received consultation two to four times, followed by 24.2% once only. Nearly 90% of mothers responded being satisfied or somewhat satisfied with consultation.

2 . Relationships Between Children's Adjustment to School and Mothers' Anxiety

The mean score on the school adjustment scale (9 items, 36 possible points) was 28.1 (SD: 5.5), and it showed a non-normal distribution (Shapiro–Wilk Test: $P < 0.001$). The mean score on the Anxiety Inventory (20 items, 80 possible points) was 42.5 (SD: 10.4) and showed a normal distribution (Shapiro–Wilk Test: $P < 0.068$). Their relationship demonstrated a negative correlation with a Spearman's rank correlation coefficient of -0.387 , $P < 0.001$ (Figure 2), indicated that the mothers' anxiety decreased as the children's adjustment to school improved.

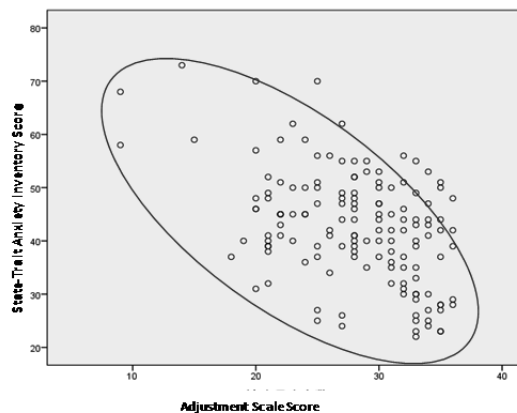


Fig. 2: Correlation Diagram between School Adjustment Scale Score and State-Trait Anxiety Inventory Score.
Spearman's rank correlation coefficient : -0.387 , $P < 0.001$

The school adjustment scale is a self-produced scale consisting of questions about whether the child is adjusting to school based in the mother's view. Cronbach's coefficient alpha was .754 ten items and was .780 in nine items. Therefore, a factor analysis was performed. One item, "child comes home immediately after school," was excluded because it did not belong with the other measurements, giving a revised total of nine items. Three factors were extracted using the oblimin method in conjunction with SPSS's Kaiser Normalization. As shown in Table 2, the first factor extracted was 'friends' (α coefficient: .678), the second factor was 'familiarity with school' (α coefficient: .809) and the third factor was 'School life' (α coefficient: .895). The reliability level was, confirmed to be sufficient.

Table 2: School Adjustment Score Factor Analysis Results

Item Content	Factor 1	Factor 2	Factor 3	α Coefficient
	Friends	Familiarity with School	School Life	
4. Often playing with friends	.997	-.233	.375	.678
3. Has close friends	.822	-.351	.295	
2. Feels familiar with the school	.364	-.994	.265	
1. Feels familiarity with school teachers	.205	-.688	.277	.809
5. Sometimes does not want to go to school	.263	-.334	.804	
9. Enjoys going to school every day	.306	-.470	.718	
6. Often being absent from school	.142	-.071	.473	.895
10. Often talks about what happened at school	.420	-.266	.434	
8. Getting home worn out from school	.287	-.101	.385	
Cumulative Contribution Ratio(%)	30.20	42.10	56.50	
Inter-Factor Coefficient	I	II	III	
	—	-.293	.379	
	II	—	-.308	
	III		—	

3. Concerns during Transition to Attending School

1) Concerns during each of the Three Periods

As shown in Table 3, following the progression through pre-enrollment, post-enrollment and the present, there was a decline in responses across all the items with the exception of Item 10 ‘other’. The most frequently chosen items were Item 7 ‘teachers understanding the disease’, Item 8 ‘friends understanding the disease’, and Item 4 ‘getting sufficient exercise’. The numbers of respondents who showed each worries or concerns significantly differed among the three periods (Chi-square test: $0.05 < p < 0.001$). There was a significant difference between the presence and the absence of the worries and concerns for each item across all three periods.

In addition, we could extract other opinions as the following: dealing with physical condition, slow learning, mental aspect of a child, improvement of school environment, and management of after-school time.

2) Primary Concerns by Periods

McNemar Test was conducted to examine if the response to the items changed over time. A significant difference was found between the response patterns of pre-enrollment and post-enrollment ($p < 0.05$) periods ($p < 0.05$) as well as between post-enrollment and present periods ($p < 0.001$).

As shown in Figure 3, the number of responses to Item 2 ‘having the strength to live through school life’ and Item 7 ‘faculty understanding the disease’ both declined from the pre-enrollment period, post-enrollment and finally to the present. In contrast, the number of responses to Item 6 ‘ability to interact with friends’ and Item 8 ‘friends understanding the disease’ increased over time.

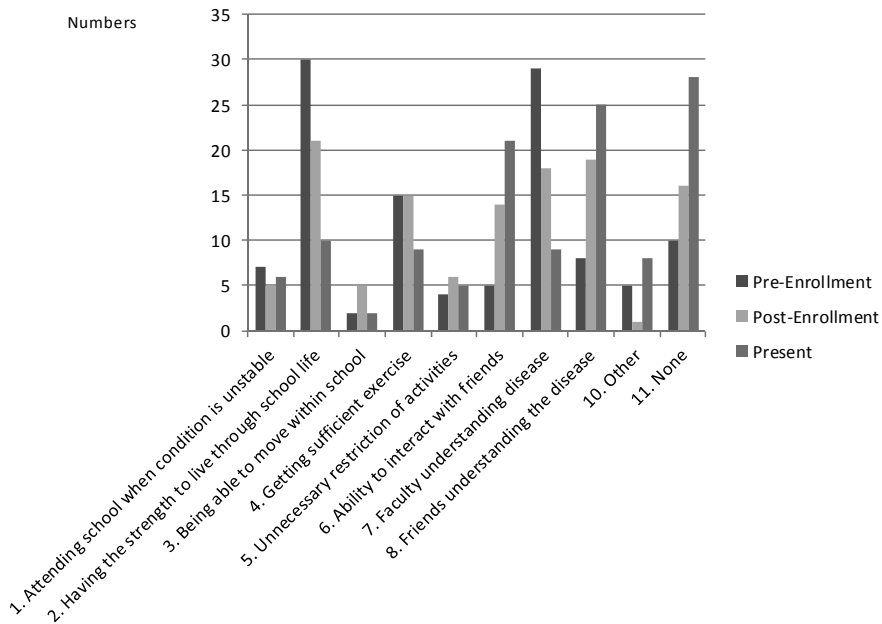


Fig.3: Primary Concern in Pre-Enrollment, Post-Enrollment, and Present

4 . Consultation Situation and Support Framework

1) Consultation Situation for Concerns

As shown in Table 3, with the exception of ‘other’ (comprising about 10%), the mean percentage of those who were able to receive consultation was 47.9%. Generally, there was a higher ratio of people receiving consultation in the pre-enrollment period, compared with the post-enrollment period and the present. The most frequent consultants were attending physicians and family members in the pre-enrollment period and homeroom teachers in the post-enrollment period and the present.

2) Specific Coping Methods for Concerns

Table 4 shows the free responses by the 143 participants by the periods and in the descending order of frequency. Responses in the pre-enrollment period were as follows: (1) consulted the persons I had previously received help from; (2) consultation opportunities received from educators and (3) explained to school myself. In the post-enrollment period and the present the responses were as follows: (1) consultation with school officials; (2) consulted the persons I had previously received help from; (3) talking with the child and (4) having opportunities to seek understanding from friends and guardians. The response rate for ‘consulted the persons I had previously received help from’ decreased from the pre-enrollment to the post-enrollment periods.

Table 3: Consultation Situation Regarding Concerns

Concern	Period	Concern (%)	Received Consultation on (%)	Number who Consulted on	person to consult (Multiple answers)																
					Board of Education	Principal	Homeroom Teacher	school nurse	Support School Faculty	Attending Physician	hospital nurses	Physiotherapist	Occupational Therapist	public health nurses	Developmental Counselor	Family Association	Relatives	Acquaintance	Other		
1. Attending school when condition is unstable	Pre-Enrollment	59 (40.7)	26 (44.1)	65	20.0%	38.5%	30.8%	29.2%	10.8%	78.5%	20.0%	3.1%	0.0%	16.9%	6.2%	20.0%	12.3%	61.5%	4.6%	18.5%	7.7%
	Post-Enrollment	41 (28.3)	20 (48.8)	54	0.0%	20.4%	70.4%	37.0%	5.6%	63.0%	11.1%	1.9%	1.9%	9.3%	5.6%	5.6%	7.4%	51.9%	7.4%	13.0%	7.4%
	Present	23 (15.9)	12 (52.2)	47	2.1%	6.4%	66.0%	31.9%	4.3%	70.2%	17.0%	2.1%	2.1%	4.3%	2.1%	4.3%	6.4%	53.2%	2.1%	17.0%	8.5%
2. Having the strength to live through school life	Pre-Enrollment	91 (62.8)	56 (61.5)	87	13.8%	26.4%	28.7%	26.4%	6.9%	66.7%	9.2%	3.4%	2.3%	11.5%	5.7%	16.1%	11.5%	49.4%	3.4%	14.9%	5.7%
	Post-Enrollment	66 (45.5)	40 (60.6)	72	2.8%	13.9%	56.9%	31.9%	4.2%	59.7%	8.3%	2.8%	1.4%	8.3%	2.8%	2.8%	6.9%	45.8%	4.2%	12.5%	5.6%
	Present	45 (31.0)	22 (48.9)	50	2.0%	14.0%	68.0%	26.0%	6.0%	68.0%	12.0%	2.0%	0.0%	4.0%	4.0%	2.0%	10.0%	54.0%	2.0%	20.0%	8.0%
3. Being able to move within school	Pre-Enrollment	40 (27.6)	14 (35.0)	43	23.3%	44.2%	41.9%	30.2%	11.6%	46.5%	7.0%	9.3%	2.3%	18.6%	7.0%	20.9%	14.0%	48.8%	4.7%	18.6%	7.0%
	Post-Enrollment	25 (17.2)	11 (44.0)	36	0.0%	13.9%	80.6%	22.2%	0.0%	41.7%	8.3%	8.3%	2.8%	8.3%	5.6%	2.8%	11.1%	44.4%	5.6%	11.1%	11.1%
	Present	14 (9.7)	7 (50.0)	31	0.0%	3.2%	77.4%	12.9%	0.0%	45.2%	9.7%	6.5%	0.0%	6.5%	6.5%	3.2%	6.5%	48.4%	3.2%	12.9%	6.5%
4. Getting sufficient exercise	Pre-Enrollment	91 (62.8)	55 (60.4)	92	12.0%	28.3%	41.3%	28.3%	6.5%	80.4%	6.5%	5.4%	1.1%	10.9%	3.3%	13.0%	12.0%	43.5%	3.3%	13.0%	4.3%
	Post-Enrollment	75 (51.7)	41 (54.7)	78	0.0%	16.7%	71.8%	30.8%	6.4%	71.8%	3.8%	3.8%	0.0%	5.1%	2.6%	1.3%	7.7%	39.7%	3.8%	10.3%	3.8%
	Present	54 (37.2)	22 (40.7)	60	0.0%	13.3%	66.7%	30.0%	3.3%	71.7%	6.7%	3.3%	0.0%	3.3%	3.3%	1.7%	6.7%	45.0%	1.7%	8.3%	6.7%
5. Unnecessary restriction of activities	Pre-Enrollment	69 (47.6)	33 (47.8)	69	13.0%	34.8%	39.1%	31.9%	7.2%	73.9%	7.2%	2.9%	1.4%	15.9%	4.3%	13.0%	11.6%	43.5%	4.3%	14.5%	2.9%
	Post-Enrollment	33 (22.8)	7 (21.2)	46	0.0%	17.4%	76.1%	34.8%	13.0%	60.9%	8.7%	2.2%	0.0%	6.5%	2.2%	2.2%	10.9%	41.3%	4.3%	10.9%	4.3%
	Present	18 (12.4)	4 (22.2)	36	0.0%	11.1%	69.4%	27.8%	13.9%	63.9%	11.1%	2.8%	0.0%	5.6%	2.8%	2.8%	11.1%	38.9%	2.8%	8.3%	5.6%
6. Ability to interact with friends	Pre-Enrollment	78 (53.8)	42 (53.8)	71	15.5%	25.4%	35.2%	19.7%	8.5%	33.8%	4.2%	4.2%	4.2%	15.5%	12.7%	19.7%	12.7%	56.3%	4.2%	23.9%	9.9%
	Post-Enrollment	56 (38.6)	26 (46.4)	57	0.0%	12.3%	71.9%	15.8%	8.8%	24.6%	5.3%	1.8%	3.5%	5.3%	8.8%	1.8%	10.5%	49.1%	3.5%	17.5%	8.8%
	Present	45 (31.0)	20 (44.4)	49	0.0%	8.2%	75.5%	12.2%	10.2%	4.1%	2.0%	4.1%	4.1%	2.0%	6.1%	2.0%	8.2%	53.1%	2.0%	24.5%	12.2%
7. Faculty understanding disease	Pre-Enrollment	112 (77.2)	80 (71.4)	102	12.7%	47.1%	46.1%	39.2%	5.9%	41.2%	8.8%	1.0%	2.0%	12.7%	3.9%	13.7%	15.7%	45.1%	3.9%	13.7%	4.9%
	Post-Enrollment	77 (53.1)	49 (63.6)	79	0.0%	22.8%	82.3%	34.2%	7.6%	27.8%	7.6%	0.0%	2.5%	2.5%	2.5%	2.5%	10.1%	38.0%	2.5%	11.4%	3.8%
	Present	48 (33.1)	23 (47.9)	59	1.7%	18.6%	81.4%	27.1%	5.1%	25.4%	6.8%	0.0%	3.4%	3.4%	3.4%	27.1%	11.9%	44.1%	1.7%	13.6%	6.8%
8. Friends understanding the disease	Pre-Enrollment	95 (65.5)	58 (61.1)	79	12.7%	39.2%	53.2%	27.8%	6.3%	26.6%	8.9%	2.5%	1.3%	13.9%	5.1%	19.0%	16.5%	54.4%	5.1%	27.8%	7.6%
	Post-Enrollment	73 (50.3)	34 (46.6)	66	0.0%	21.2%	78.8%	27.3%	4.5%	21.2%	4.5%	0.0%	0.0%	3.0%	4.5%	3.0%	12.1%	51.5%	4.5%	15.2%	4.5%
	Present	73 (50.3)	29 (39.7)	58	1.7%	13.8%	75.9%	19.0%	5.2%	20.7%	6.9%	0.0%	0.0%	1.7%	6.9%	1.7%	15.5%	53.4%	1.7%	15.5%	6.9%
9. Parent being able to make requests for child's school	Pre-Enrollment	64 (44.1)	27 (42.2)	59	15.3%	37.3%	44.1%	27.1%	5.1%	28.8%	6.8%	3.4%	1.7%	18.6%	5.1%	13.6%	18.6%	59.3%	8.5%	20.3%	6.8%
	Post-Enrollment	47 (32.4)	20 (42.6)	52	0.0%	19.2%	61.5%	25.0%	9.6%	23.1%	5.8%	0.0%	0.0%	3.8%	3.8%	3.8%	15.4%	57.7%	9.6%	19.2%	3.8%
	Present	37 (25.5)	15 (40.5)	46	0.0%	17.4%	58.7%	23.9%	8.7%	21.7%	6.5%	0.0%	0.0%	2.2%	6.5%	2.2%	21.7%	54.3%	4.3%	17.4%	4.3%
10. Other	Pre-Enrollment	13 (9.0)	1 (7.7)	11	54.5%	63.6%	54.5%	45.5%	36.4%	54.5%	18.2%	0.0%	0.0%	54.5%	27.3%	9.1%	36.4%	9.1%	36.4%	9.1%	
	Post-Enrollment	12 (8.3)	1 (8.3)	10	0.0%	10.0%	70.0%	40.0%	0.0%	50.0%	20.0%	0.0%	0.0%	20.0%	30.0%	0.0%	20.0%	40.0%	10.0%	30.0%	10.0%
	Present	13 (9.0)	2 (15.4)	10	10.0%	20.0%	60.0%	30.0%	0.0%	60.0%	20.0%	0.0%	0.0%	10.0%	20.0%	0.0%	30.0%	40.0%	10.0%	20.0%	10.0%
Average of "Concerns" and "Received Consultation" (excluding 10. Other) : 47.9%																					

3) Helped in Dealing with Concerns

Table 4 presents the free responses by the 105 participants in the descending order of frequency. The pre-enrollment period: (1) The provision of information, which included opportunities to speak to the school, school visits, and understanding the situation of environmental maintenance. (2) Liaison and coordination with the school, which included bridge-building with people they had interacted with in the past (including attending physicians, health nurses and child nurses) and support from coordinators. The post-enrollment period and the present: (1) The provision of information about school life, which included close contact with homeroom teachers and interactions with adjunct faculty. (2) Understanding school rules, which included having a place of discussion and advice from outside the school, including attending physicians. (3) Being listened to; the last item was common to both the pre-enrollment and post-enrollment periods. The persons who listened to the mothers in the pre-enrollment period were child minders, public health nurse and hospital nurses, whereas those in the post-enrollment were school nurses, school counsellors and guardians (other mothers), except those attending physicians, family associations and family members were listeners present in both periods.

Table 4.:Helpful Coping Methods for Concerns/Helpful Support (Free Comments)

	Pre-Enrollment	Post-Enrollment/Present
Specific Coping Methods	①Consulting people I have previously interacted with: Attending physician, childminder, public health nurse, family association, acquaintances, any type of ② Opportunities to consult with educators: Board of Education, School consultation, School health examination, Principal, Homeroom Teacher, school nurse ③ Explaining to School by Oneself: Preliminary visitation, Putting records in order, Participating in study group	①Consultation with school officials: Homeroom teacher, school nurse, principal, head teacher, school counsellor ②Consulting with people I have previously interacted with (reduced): Attending physician, kindergarten principal, public health nurses, family associations, acquaintances ③Speaking with the child ④Opportunities to be understood: Friends, guardians
n = 143		
Helpful Support	①Providing information before enrollment: Opportunities to speak with school, school visits, environmental maintenance ②Liaison and coordination with school: With attending physician, health nurse, and child nurse, with coordinators ③ Being listened to: By attending physicians, family associations, family, by childminder, public health nurses, hospital nurses	①Providing information about school life: From homeroom teacher, adjunct faculty ②Understanding school rules: Having a place for discussion, advice from attending physician, and outside the school ③ Being listened to: By attending physicians family associations, family, by homeroom teacher, school nurse, school counsellor, guardian
n = 105		

4) Support Needed in the Future

As shown in Figure 4, the most frequent response was advice regarding school life by specialists was 40%, followed by support for the child's mental development 37.2%, specialists visiting schools to give advice to faculty 32.4%, deployment of coordinators to connect to related agencies 30.3% and positive interactions with attending physicians 24.8%.

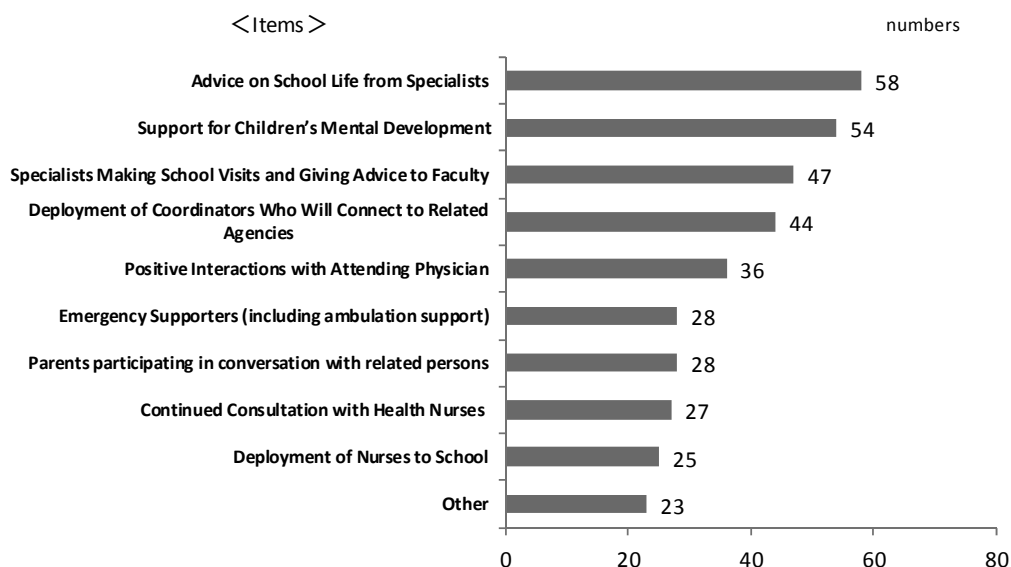


Fig. 4: Number of Support items expected to be necessary in the future (Multiple answers : n=145)

5 . Relationships between Basic Characteristics and Children's School Adjustment

Table 5 shows the items that yielded significant differences. For the child's diagnostic period, the adjustment level was significantly lower in the order of after birth, upon birth and before birth. For the daily life activities in school life, children who were not independent in elimination, communication and movement conditions showed significantly lower scores compared with the independent group. Regarding class divisions, children in support classes were significantly low compared with the children in regular classes. Regarding the means of commuting, adjustment was significantly lower in the order of transport provided by guardians, walking by oneself and using a school bus.

Catalyst for consultation, adjustment was significantly lower in the order of school and board of education, self and no consultation. Satisfaction with consultation, adjustment was significantly lower in the order of somewhat dissatisfied, mostly satisfied and satisfied.

Table 5: Comparison of School Adjustment Scales among Children with Different Attributes n=145

Item		Subjects	%	Median	IQR	p-value
Diagnostic Period	After Birth	76	52.4	30.0	26.0–33.0	0.001 * *
	Upon Birth	62	42.8	28.0	21.0–31.0	
	Before Birth	7	4.8	23.0	21.0–28.0	
Elimination	Independent	131	90.3	28.0	23.0–31.3	0.002 * *
	Assisted (including partially assisted)	14	9.7	25.0	20.3–28.8	
Communication	Independent	130	89.7	28.0	23.5–31.0	0.005 * *
	Assisted (including partially assisted)	15	10.3	25.0	17.5–28.5	
Movement	Independent	131	91.6	28.0	24.0–31.8	< 0.000 * * *
	n=143 Assisted (including partially assisted)	12	8.4	24.0	21.0–25.3	
Class	Regular Class	119	82.1	28.0	22.0–31.3	0.016 *
	n=141 Support Class	24	16.6	26.5	23.0–30.0	
Means of Commuting	Walk by Self	109	75.2	30.0	25.0–33.0	0.002 * *
	School Bus	5	3.4	29.0	27.5–30.5	
	Transport by Guardian	25	17.2	24.0	21.0–28.0	
	Transported Partway	1	0.7			
	Other	5	3.4	32.0	26.0–33.5	
Catalyst for Consultation	Self	78	55.3	28.0	22.8–32.0	0.003 * *
	No Consultation	44	31.2	32.5	27.0–35.0	
	n=141 School	6	4.5	28.0	24.0–30.3	
	Board of Education	4	2.5	23.0	21.3–24.8	
	Other	9	5.7	28.0	24.0–30.5	
Satisfaction with Consultation n=102	Mostly Satisfied	55	53.9	27.0	22.0–30.0	0.02 *
	Satisfied	38	37.3	30.0	25.0–33.0	
	Somewhat dissatisfied	9	8.8	30.0	19.5–31.0	

p<0.05 * p<0.01 * * p<0.001 * * * Mann-Whitney U Test, Kruskal Wallis Test

6 . Relationships between Mothers' Anxiety and Each Item

The participants were divided into the high-anxiety group, which scored 40 or higher on the Anxiety Inventory, and the low-anxiety group, which scored 39 or lower. A chi-square test was performed for each item.

1) Relationships with Basic Characteristics

Table 6 shows the items that had a significant difference. The ratio of the statistically significant items in the high-anxiety group was significantly higher among participants with children in lower grades, first-born children compared with second-born children, and people with medical care compared with those without the same. The ratio of the significant items in the high-anxiety group was significantly higher among participants for whom the pre-enrollment was the most anxious period.

Table 6: Relationship Between Children's Attributes and Mother's Anxiety n=145

		Low-Anxiety Group		High-Anxiety Group		P-value
		n	%	n	%	
Total		53	36.6	92	63.4	
Grade	First Grade	16	29.6	38	70.4	0.027 *
	Second Grade	15	30.0	35	70.0	
	Third Grade	22	53.7	19	46.3	
Medical Care	Present	8	21.6	29	78.4	0.029 *
	Absent	45	41.7	63	58.3	
Birth Order	First Child	9	22.5	31	77.5	0.030 *
	Second Child	44	41.9	61	58.1	
Anxious Period n=135	Pre-Enrollment	7	17.5	33	82.5	0.019 *
	Enrollment/Immediately Before Enrollment	25	42.4	34	57.6	
	Post-Enrollment	13	52.0	12	48.0	
	Present	5	45.5	6	54.5	

p<0.05 * p<0.01 * * Chi-Square Test

2) Relationships with Concerns

As shown in Table 7, the ratio of the high anxiety group was significantly higher for people who had the following concerns than for people who did not: Item 1 (condition) the post-enrollment and the present, Item 4 (exercise) the pre-enrollment and the post-enrollment, Item 5 (restriction of activity) the pre-enrollment, Item 6 (interaction with friends) in all periods, Item 7 (faculty understanding) the pre-enrollment and the post-enrollment and Item 8 (friends understanding) in all periods.

3) Relationships with Consultation for Worries and Concerns

As shown in Table 8, the proportion of subjects who did not receive consultation was higher in the high-anxiety group than the low- anxiety group.

Table 7: Relationship between Mother's Anxiety and Concerns

Concerns	Period	Total	Low-Anxiety Group		High-Anxiety Group		P-Value	
		n	n	%	n	%		
		145	53	36.6	92	63.4		
1. Attending school when condition is unstable	Pre-Enrollment	Yes	13	22.0	46	78.0	0.002	* *
	Enrollment	No	40	47.6	44	52.4		
	Post-Enrollment	Yes	12	29.3	29	70.7	0.221	
	Enrollment	No	41	40.2	61	58.8		
	Present	Yes	4	17.4	19	82.6	0.033	*
	Enrollment	No	49	40.8	71	59.2		
2. Having the strength to live through school life	Pre-Enrollment	Yes	29	31.9	62	68.1	0.089	
	Enrollment	No	24	46.2	28	53.8		
	Post-Enrollment	Yes	24	36.4	42	63.6	0.873	
	Enrollment	No	29	37.7	48	62.3		
	Present	Yes	14	31.1	31	68.9	0.318	
	Enrollment	No	39	39.8	59	60.2		
3. Being able to move within school	Pre-Enrollment	Yes	11	27.5	29	72.5	0.140	
	Enrollment	No	42	40.8	61	59.2		
	Post-Enrollment	Yes	8	32.0	17	68.0	0.564	
	Enrollment	No	45	38.1	73	61.9		
	Present	Yes	5	35.7	9	64.3	0.912	
	Enrollment	No	48	37.2	81	62.8		
4. Getting sufficient exercise	Pre-Enrollment	Yes	25	27.5	66	72.5	0.002	* *
	Enrollment	No	28	53.8	24	46.2		
	Post-Enrollment	Yes	22	29.3	53	70.7	0.044	*
	Enrollment	No	31	45.6	37	54.4		
	Present	Yes	15	27.8	39	72.2	0.073	
	Enrollment	No	38	42.7	51	57.3		
5. Unnecessary restriction of activities	Pre-Enrollment	Yes	18	26.1	51	73.9	0.011	*
	Enrollment	No	34	46.6	39	53.4		
	Post-Enrollment	Yes	8	24.2	25	75.8	0.092	
	Enrollment	No	44	40.4	65	59.6		
	Present	Yes	4	22.2	14	77.8	0.175	
	Enrollment	No	48	38.7	76	61.3		
6. Ability to interact with friends	Pre-Enrollment	Yes	21	26.9	57	73.1	0.006	* *
	Enrollment	No	31	49.2	32	50.8		
	Post-Enrollment	Yes	12	21.4	44	78.6	0.002	* *
	Enrollment	No	40	47.1	45	52.9		
	Present	Yes	11	24.4	34	75.6	0.036	*
	Enrollment	No	41	42.7	55	57.3		
7. Faculty understanding disease	Pre-Enrollment	Yes	36	32.1	76	67.9	0.022	*
	Enrollment	No	16	55.2	13	44.8		
	Post-Enrollment	Yes	22	28.6	55	71.4	0.025	*
	Enrollment	No	30	46.9	34	53.1		
	Present	Yes	14	29.2	34	70.8	0.173	
	Enrollment	No	38	40.9	55	59.1		
8. Friends understanding the disease	Pre-Enrollment	Yes	26	27.4	69	72.6	0.001	* *
	Enrollment	No	26	56.5	20	43.5		
	Post-Enrollment	Yes	21	26.7	58	73.4	0.004	* *
	Enrollment	No	31	50.0	31	50.0		
	Present	Yes	20	27.4	53	72.6	0.016	*
	Enrollment	No	32	47.1	36	52.9		
9. Parent being able to make requests for child's school life	Pre-Enrollment	Yes	20	31.3	44	68.8	0.185	
	Enrollment	No	32	42.1	44	57.9		
	Post-Enrollment	Yes	16	34.0	31	66.0	0.589	
	Enrollment	No	36	38.7	57	61.3		
	Present	Yes	12	32.4	25	67.6	0.489	
	Enrollment	No	40	38.8	63	61.2		
10. Other	Pre-Enrollment	Yes	4	30.8	9	69.2	0.229	
	Enrollment	No	8	53.3	7	46.7		
	Post-Enrollment	Yes	3	25.0	9	75.0	0.098	
	Enrollment	No	9	56.3	7	43.8		
	Present	Yes	2	15.4	11	84.6	0.006	
	Enrollment	No	10	66.7	5	33.3		

p<0.05 * p<0.01 ** p<0.001 *** Chi-Square Test

Table 8: Having Consultation or not and Anxiety of Mothers with concerns

Consultation	Low-Anxiety Group		High-Anxiety Group		P-value
	n	%	n	%	
Yes	46	90.2	68	77.3	0.046 *
No	5	9.8	20	22.7	
Total	51	100.0	88	100.0	

DISCUSSION

1. When we looked at School Life Situation of Children under medical treatment for a long time during the Transition to School Attendance approximately 50% of the diagnoses were given before birth or upon birth, indicating early onset of disease, while over 90% received inpatient/or outpatient care or went through observational follow-ups, and 25% of children required medical care. Thus, there is a necessity for these children to continue to visit medical institutions during school life. Additionally cooperation between schools and medical institutions is necessary. While the majority of these children are enrolled in regular classes and are independent in their daily life, an examination of the factors for the children's low school adjustment scale scores demonstrates that independence in daily life activities, independence in means of commuting, early diagnosis before birth, and enrollment in support classes are related, and support for children with low life independence is required⁹⁾. Regarding the reasons for school attendance consultation, the school adjustment scale score became significantly lower in the order of consultation from the school or board of education, consultation from self, and no consultation, may suggest that children whose mothers cannot seek consultation, or who must seek consultation elsewhere, may have more difficulty adjusting to school. Given that participants who reported being satisfied with the consultation having a significantly higher school adjustment score than others, there is a need for a school attendance consultation framework that people who cannot seek consultation can be satisfied with. To engage such participants early on, it is important to strengthen the cooperation between community health care and schools before school attendance¹⁰⁾.

Based on the situation of school life during the transition to school attendance, promoting children's school adjustment will require support for independence in school life, environmental maintenance, selection of a school that matches the condition of children, a class framework and fulfillment of consultation prior to attending school

2 . Changes in Mother's Concerns during Transition to School Attendance

The most frequent responses in the pre-enrollment, the post-enrollment and the present periods were 'faculty understanding the disease', 'friends understanding the disease', 'having the strength to live school life' and 'getting sufficient exercise'. This indicates the necessity for an adequate understanding of the disease and consideration for the condition, such as strength or motor restrictions due to the disease. Worries and concerns of the parents decreased as time passed, 'friends understanding the disease' did not change during post-enrollment and present Approaches to seek understanding of children with disease from other children post-enrollment is necessary. Furthermore, 'ability to interact with friends' and 'friends' understanding of the disease' increased as the primary concern, indicating the importance of approaches to get other children to understand. 'Coping with physical condition', 'slow learning', 'child's mental aspect', 'school environment improvement' and 'after-school coping' were listed as opinions for other concerns, indicating the need for consideration of physical condition and learning, support for the child's mental aspects as they grow and support for regional livelihood in both school and the environment.

3 . Mothers' Anxiety

The mean score on the Anxiety Inventory was 42.5 points, which is higher than that of average women. According to a study by Nakazato et al, women 25 to 54 years old showed the score of 39.5⁷⁾. This indicates that their anxiety is great and probable to be continuous, and continuation of consultation that address mothers' feelings will be necessary. As there was a negative correlation between the child's school adjustment and the mother's anxiety, it could be said that an improvement in the child's school adjustment can alleviate the mother's anxiety. Interactions with mothers of children in the first grade, who are first-borns and who require medical care, which were the items with a significantly high ratio of the high-anxiety group, need to have highest priority. Many parents responded that particularly the pre-enrollment was the most anxious period, demonstrating the need for the fulfillment of consultations at nursery centers kindergartens, municipalities, and health care centers that they interact with prior to school attendance. The fulfillment of a consultation system that involves cooperation with medical institutions and other related facilities, and cooperation of schools and the board of education is required. Judging by the concerns of the mothers during the transition to school attendance, the stability of the child's condition, sufficient exercise, activity restrictions, interactions with friends, faculty understanding of the disease and friends' understanding of the disease are common

concerns among high-anxiety mothers. It is necessary to predict these factors and take them into consideration. Since high-anxiety mothers particularly have concerns regarding interaction with friends and friends' understanding of the disease throughout pre-enrollment, post-enrollment and present, guidance of other children at school is necessary; other children are influential to a child with disease¹¹⁾.

4 . Support Content

Nearly half of the participants with concerns did not receive consultation, and fewer received it in the post-enrollment and the present periods compared with the pre-enrollment, indicating that there may be fewer chances for consultation in the post-enrollment¹¹⁾, and that consultants are not as close. As nearly 70% of consultants after enrollment are homeroom teachers, there may be few settings for consultation outside the school, which leads to a situation of being unable to connect with consultation¹²⁾.

For opinions on specific coping methods for concerns, 'consulting with people I have interacted with in the past' was the most frequent pre-enrollment, and this declined through the progression to post-enrollment and present. In post-enrollment and the present periods, 'speaking with the child' and 'gaining the understanding of friends and their guardians' were present, showing that the mothers cope with their own approaches as their child grows, and to gain the understanding of those around them. To summarize the opinions of support that helps with concerns, there were 'obtaining information from the school by specifically speaking to or visiting the school', 'someone I had interacted with before coordinating to gain the school's understanding' and 'having a consultant listen to me from pre-enrollment to the present', indicating the need for a continuing consultation system and chances to obtain specific information during the transition to school attendance¹³⁾. Regarding future interactions, it is necessary for specialists to intervene with the school, related institutions to continue cooperation, and provide support for the child's mental development that accompanies their growth.

Finally, regarding the limitations of this study, there was a small sample size of 145(response rate: 34.7%), and the children in the study had one of five conditions with a bias in the number of conditions. Since this study employed a retrospective way questionnaire, the responses depend on memory. This suggests that this data is not generalizable. Future research should add information that expands the participants' conditions, investigate an index that can provide early prediction on the necessity of support based on these results and review the appropriate support content.

CONCLUSIONS

While the concerns during the transition to school attendance declined with the passage of time, interactions with friends increased as the primary concern. As people are not able to receive consultation for this, it is necessary to have a consultation framework continuing from pre-enrollment and chances to obtain specific information. The necessity to prioritize assistance in daily life activities and means of commutation, early diagnosis from before birth, and support for low-independence children such as those enrolled in special classes has been indicated from the children's school adjustment situation, and support for children pre-enrollment, in first grade, who are first-borns and who require medical care, and their mothers, has been indicated from the mothers' anxiety situation.

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