

# Distress felt by children with developmental disorders and their families when consulting at general medical institutions

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## KEY WORDS

children with developmental disorder, family, distress felt, consulting at general medical institution, medical staff

### Introduction

The number of developmental disorder specialists is still limited in Japan; therefore most children with developmental disorders consult general medical institutions when they contract a common disease, such as an infection. However, since consultations by general medical institutions are quite different from the normal environment for children with developmental disorder, often it causes them to panic<sup>1,2)</sup>. Under such circumstances, there have been reports<sup>3)</sup> that some medical staff reproach or display a callous attitude towards such children, causing psychological damage to the patient and their parents. Also, there have been some cases of refusal of hospitalization and outpatient care because of the developmental disorder<sup>4)</sup>, and thus some consider that medical care at general hospitals was painful experience for the children and their families.

It is, therefore, extremely important for the medical staff to empathize and understand this distress so that children with developmental disorders can be consulted without anxiety at general medical institutions.

Hence, the purpose of this study is to investigate and clarify a) the consultation status of children with developmental disorders at the general medical institutions and b) the distress felt by the children and their family at that time.

### Definition of Terms

- **Specialized medical institutions:** Institutions performing rehabilitation and medical practice specialized in developmental disorders.
- **General medical institutions:** Institutions such as general hospitals, clinics, and practitioners who practice pediatrics and internal medicine.

### Methods

Subjects of this study were families of children with developmental disorders. People, who are registered to 34 organizations that have consented to the research, have been distributed the questionnaire through their facilities or organizations and returned the replies by stamped addressed envelope. The study was carried out between July and December 2010.

### Study contents

- Background; Attributes of subjects; age, family type, residential area, age and gender of child, diagnosis of disease.
- Situation for medical consultation; Consultation with specialized medical institutions, and general hospitals.
- Distress felt during consultation at general hospitals.
- Families' efforts and families' requests to medical staffs to receive the consultation at general hospitals.

### Data analysis

Responses about feelings of anxiety to receiving consultations at general medical institutions, distress felt during the consultation and dissatisfaction to medical staff, were aggregated and analyzed as a percentage. For the diagnoses, references used were DSM-IV-TR<sup>5)</sup> and the classification of Sugiyama<sup>6)</sup> to classify them into the category of "Pervasive developmental disorder (PDD)". "High-functioning pervasive developmental disorder (HPDD)", "Pervasive developmental disorder accompanied by intellectual disorder (PDD with ID)", and then compared the feeling of anxiety towards the consultation and the distress felt at the time of diagnosis by the disorder types. From free-style descriptions, the contents were qualitatively analyzed and classified into categories and then aggregated to determine the percentage. For percentage comparison by disorder groups, "HPDD",

"PDD", "PDD with ID",  $\chi^2$  test was conducted. Statistical analyses were performed using IBM SPSS Statistics software (version 23.0) for Windows. A level of significance less than 5% was considered statistically significant.

### Ethical consideration

The subjects were explained, a) the purpose of the research, b) that it is anonymous and thus individuals cannot be identified, c) that no disadvantage is incurred by not participating to the research, d) that consent will be construed by the return of the questionnaire, e) that the results are used only for the purpose of research, f) the data is stored in a lockable location. The study was approved by the ethical committee of the Graduate School of Medical Sciences and College of Medical, Kanazawa University (approval No. 244).

## Results

### 1. Attributes of subjects

Of 392 responses (response ratio: 45.6%), there were 314 valid responses (80.1%).

Table 1 shows the attributes of the subjects. The average age of respondents was  $41.6 \pm 5.4$  years, and 93.0% were mothers, which was highest. Nuclear families were high with 70.4%, as for the residential areas, the central region was 31.8%, Kanto region was 28.7%. The average age of children was  $9.9 \pm 3.3$  years, and 79.6% of them were boys and 20.4% were girls, thus boys exceeded girls significantly. "PDD with ID" was 30.9%, "PDD" was 30.9%, "HPDD" was 31.8%, others were 6.4%.

### 2. Situation on medical consultation

Seventy-two point nine percentage of children with developmental disorders have consulted the specialized medical institutions, and percentage of "HPDD" was significantly higher ( $p \leq .05$ ). Of those only 41.5% have received the treatment for standard diseases, such as infection at the same specialized medical institution. Children who went to personal general medical institution have accounted for 88.5%. And 30.6% of the respondents answered that their children have been hospitalized and of which 32.1% had unpleasant experience.

### 3. Feeling of difficulties on consulting general institutions

During the general medical institutions consultation, 75.5% of families felt anxiety and the reason for which were "if the child can receive consultation without maladjusted behavior", "if the medical staff can understand the disorder", and "if the child can wait calmly until

Table 1. Attributes of subjects

	Number(%)
<b>Respondents</b>	
Mother	292 (93.0)
Father	14 ( 4.5)
Others	8 ( 2.5)
Age of Respondents (Average years $\pm$ SD)	41.6 $\pm$ 5.4
<b>Family Type</b>	
Parents and children	221 (70.4)
Parents and children and Grandparents	53 (16.9)
Others	40 (12.7)
Age of Children (Average years $\pm$ SD)	9.9 $\pm$ 3.3
<b>Sex of Children</b>	
Boy	250 (79.6)
Girl	64 (20.4)
<b>Diagnosis</b>	
PDD with ID <sup>a</sup>	97 (30.9)
PDD <sup>b</sup>	97 (30.9)
HPDD <sup>c</sup>	100 (31.8)
Others <sup>d</sup>	20 ( 6.4)

Note. a: PDD with ID; "Pervasive Developmental Disorder with Intellectual disorder".  
b: PDD; "Pervasive Developmental Disorder" not accompanied by mental retardation, autistic disorder, atypical autism, and pervasive developmental disorder not otherwise specified are defined as PDD. c: HPDD; "High-functioning Pervasive Developmental Disorder", Asperger's syndrome, high-functioning autism are defined as HPDD. d: Others; are not diagnosed.

the consultation". In actual fact, 35.0% of families have experienced abandoning the consultation because the child disliked the consultation and the treatment.

Of the families, who felt that the children's disorders were not understood by medical staff; it revealed that 49.4% was about the doctors and 33.8% was about the nurses. Dissatisfaction ratios were, 48.7% to the doctors' approach and 34.4% to the nurses' approach. Reason for the most dissatisfaction towards both the doctors and the nurses was "inconsiderate and frosty approach", of which 44.5% was toward the doctors and 33.6% was toward the nurses. By the doctors, "Annoying look" and "Condescending expression toward the child with disorder" and by the nurses, "Told to the child it is undignified when a big boy cries like a little one" and "Criticizing the parent". Also, 26.7% felt dissatisfaction with the lack of knowledge of developmental disorders by the nurses and 20.0% who were unwilling to tell the medical staff that their child has disorder.

### 4. Feeling of difficulties on consulting general institutions by the type of disorder (Table 2)

When comparing feelings around consultations by the disorder type, the type who answered stating "had anxiety at the consultation", "felt irritation and dissatisfaction to the doctor's approach" and "had an experience of

abandoning the consultation because the child disliked the consultation”, was significantly higher in “PDD with ID”. On the other hand, with “HPDD”, significant proportion answered stating “they didn’t want the medical staff to notice the disorder”; it revealed that feelings of the families differ depending on the type of disorder.

#### **5. Family efforts to receive the consultation**

Forty nine point six percentage of families have explained to their child within the scope of their understanding the purpose and planned treatment and the waiting time of the consultation, such as “letting the child have the prospect of consultation”. Also, “prior-explanation of the characteristics and disorder of the child to medical staff” was seen in 31.3% of the responses. Another effort for “choosing the period of least waiting time” was seen 18.4%.

#### **6. Families’ requests to medical staffs to receive the consultation at general hospitals**

What families request to medical staff when receiving the consultation at general medical institutions are, “Can forecast the waiting time” 38.0%, “Consideration for the waiting room” 34.0%, “Medical staff is knowledgeable with developmental disorders” 29.6%, and “Support to have a child understand the consultation procedure” 20.8%.

### **Discussion**

Families of children with developmental disorders face challenges that place them at risk for higher levels of stress than mothers of typically developing children<sup>7-8)</sup>. In this study, as many as 76% of the family harbored anxiety about consultations at general hospitals; this means that when the children with developmental disorders receive consultations the families were not only concerned about the child’s medical condition but also if they could receive adequate treatment. The reasons for the anxiety that families cited were thought to be past unpleasant experiences. In fact, 35% of children had an experience of abandoning the consultation. They cannot understand the content and procedures of the consultation<sup>9)</sup>.

As children with developmental disorders have hypersensitivity they can feel unimaginable pain and fear towards the sudden cries of other children, sounds of examinations and treatments, bright lights and so forth. It is said, that by evoking memory flashbacks of being forcibly held down and other unpleasant consultations, panic can even be induced at a consultation room which has never been visited before<sup>10)</sup>. Medical staffs were not

only misunderstanding these children’s inappropriate behavior but also have hurt the feelings of children and families<sup>11)</sup>. Responses that families didn’t want the medical staff to know that the children had disorder were significantly higher from the families of high-functioning pervasive developmental disorder (HFPDD). These children tended not to have the intellectual disorder, which meant the language development delay is very slight. As such, this group of children seemed as if they have no developmental issues. However, the developmental disorder behavior shown by these children can be difficult to understand by onlookers and can often be misinterpreted as the result of the parent’s disciplining.

The medical staff should consider the efforts made by the families to prepare for the consultation and deepen their understanding of developmental disorders<sup>12)</sup>. Both the environment and consultation methods should be improved so that children and families can visit at ease.

Although in recent years the awareness of the developmental disorders has grown and the approaches by the general medical institutions are thought to have improved<sup>13)</sup>, it is important for the medical staff to be more sympathetic to the feeling of the families by accounting for the child’s past experiences, as confirmed in this report, and that an appropriate support model accounting for the child’s characteristics should be provided.

### **Limitation and Challenge**

As this study is a retrospective research from the past experiences, the obtained results of this time do not faithfully reflect the current situation. Moreover, because we don’t know the occurrence time of each experience, the analysis by the age of the child has not been carried out, and remains as a future challenge.

### **Conclusion**

When the children with the developmental disorder consulted general medical institutions in Japan, 75.5% of family harbored anxiety, and felt distressed during consultations. It is, therefore, important that the medical staff should not forget to be more sympathetic to the anxieties of the parents by sincerely understanding the families’ pain caused by their past experiences.

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Table 2. Feeling of difficulties on consulting general institutions by the type of disorder

	Total (n=294)	PDD with ID <sup>a</sup> (n=97)	PDD <sup>b</sup> (n=97)	HPDD <sup>c</sup> (n=100)	$\chi^2$	p-value
Had anxiety at the consultation						
Yes	223(75.8)	84(86.6) **	76(78.3)	63(63.0)	22.5	<.001
Neither	27( 9.2)	6( 6.2)	12(12.4)	9( 9.0)		
No	44(15.0)	7( 7.2)	9( 9.3)	28(28.0) **		
Felt irritation and dissatisfaction to the doctor's approach						
Yes	145(49.3)	59(60.8) *	48(49.5)	38(38.0)	10.4	.034
Neither	50(17.0)	10(10.3)	16(16.5)	24(24.0) *		
No	99(33.7)	28(28.9)	33(34.0)	38(38.0)		
Had an experience of abandoning the consultation						
Yes	105(35.7)	45(46.4) *	35(36.1)	25(25.0)	13.5	.009
Neither	34(11.6)	15(15.5)	9( 9.3)	10(10.0)		
No	155(52.7)	37(38.1)	53(54.6)	65(65.0) **		
Didn't want the medical staff to notice the disorder						
Yes	60(20.4)	9( 9.3)	14(14.4)	37(37.0) **	47.4	<.001
Neither	46(15.6)	4( 4.1)	21(21.7) *	21(21.0) *		
No	188(64.0)	84(86.6) **	62(63.9)	42(42.0)		

Note. Number(%). a: PDD with ID; "Pervasive Developmental Disorder with Intellectual disorder". b: PDD; "Pervasive Developmental Disorder" not accompanied by mental retardation, autistic disorder, atypical autism, and pervasive developmental disorder not otherwise specified are defined as PDD. c: HPDD: "High-functioning Pervasive Developmental Disorder", Asperger's syndrome, high-functioning autism are defined as HPDD. \*, Statistically significant association by adjusted residual analysis (p<.05), \*\*, Statistically significant association by adjusted residual analysis (p<.01).

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