

Supplementary 1: Predictive factors of primary caregivers' QoL (N=143)

	<i>n/M ±SD</i>
<u>Primary caregivers</u>	
Age of onset of children with IEM	2.24 ± 3.25
The number of times visiting a hospital per year for children with IEM	11.5 ± 15.4
12 times per year and under	117
24 times per year and under	12
over 25 times per year	14
The number of difficult things related to raising a child with IEM*	3.7 ± 2.8
The lack of information about disease and treatment of IEM	77
I become nervous when my child with IEM eats out or has sleepovers	77
I struggle with the difficulty of providing diet therapy for my child with IEM	59
My IEM child's growth and development are delayed	57
People around them lack understanding of the disease and children with IEM	45
I do not know what to do when my IEM child's symptoms appear	37
My child with IEM is vulnerable to infection	35
Medical professionals who do not know IEM well cope with my child with IEM	33
There is no one who I can talk to about difficult things related to raising a child with IEM	28
My child with IEM frequently admits to and discharges from a hospital	26
I do not know how to cope with society with children with IEM	19
I have experienced social discrimination and prejudice because my child has IEM	18
Others	50
None	18
The number of anxieties related to raising a child with IEM*	3.5 ± 1.9
I have anxiety about new symptoms appearing in the future	108
I have anxieties about the burden of medical costs after my child with IEM becomes 20 years old	96
I have anxiety about my IEM child visiting hospital because there are many medical professionals who do not know IEM well	85
I have anxiety about symptom episodes when my child with IEM is sick	74
I have anxiety about delayed growth and development in the future	67
I have anxiety about symptom episodes when my child with IEM in school or goes out	63
Others	46
None	35

*Multiple answers allowed

Supplementary 1: (continued) Predictive factors of primary caregivers' QoL (N=143)

	<i>n/M ±SD</i>
<u>Primary caregivers</u>	
Degree of distress about caring for a child with IEM	-
Strongly disagree	13
Disagree	25

Undecided	39
Agree	54
Strongly agree	12
The number of eligible information resource of their child's disease and	2.7±1.1
Special doctor of metabolism	114
Patient group / Parental group	90
Internet	71
Primary care doctor	13
Home-care nurse	11
Outpatient nurse	8
Public health nurse	5
No Resource	2
Satisfaction in the relationship with the child with IEM	-
Very satisfied	86
Satisfied	16
Neither	36
Dissatisfied	4
Very dissatisfied	1
Satisfaction in the relationships within the family	-
Very satisfied	73
Satisfied	23
Neither	41
Dissatisfied	4
Very dissatisfied	2
Household income	-
Wealthy	12
Slightly wealthy	21
Average	77
Slightly poor	17
Poor	16
Degree of understanding their child with IEM by people around them	-
Very good	41
Good	92
Normal	10
Not good	0
Bad	0

*Multiple answers allowed

Supplementary 2: Predictive factors of partners' QoL (N=86)

	<i>n / M ± SD</i>
Partners	
The number of anxieties related to raising a child with IEM*	3.4±1.7
I have anxiety about new symptoms might appear in the future	66
I have anxieties about the burden of medical costs after my child with IEM becomes 20 years old	56
I have anxiety about my IEM child visiting hospital because there are many medical professionals who do not know IEM well	47
I have anxiety about symptom episodes when my child with IEM is sick	47

I have anxiety about delayed growth and development in the future	47
I have anxiety about symptom episodes when my child with IEM in school or goes out	32
Others	40
None	6
Degree of distress about caring their child with IEM	-
Strongly disagree	11
Disagree	20
Undecided	22
Agree	28
Strongly agree	5

*Multiple answers allowed

Supplementary 2: (continued) Predictive factors of partners' QoL (N=86)

	<i>n/M ±SD</i>
<u>Partners</u>	
Satisfaction in the relationship with the child with IEM	-
Very satisfied	40
Satisfied	11
Neither	36
Dissatisfied	0
Very dissatisfied	0
Satisfaction in the relationships within the family	-
Very satisfied	39
Satisfied	11
Neither	33
Dissatisfied	3
Very dissatisfied	0
Household income	-
Wealthy	5
Slightly wealthy	13
Average	46
Slightly poor	13
Poor	9
Degree of understanding their child with IEM by people around them	-
Very good	39
Good	11
Normal	33
Not good	3
Bad	0

%/range

0-14

0-100

81.8%

8.4%

9.8%

0-11

53.8%

53.8%

41.3%

39.9%

31.5%

25.9%

24.5%

23.1%

19.6%

18.2%

13.3%

12.6%

35.0%

12.6%

0-7

75.5%

67.1%

59.4%

51.7%

46.9%

44.1%

31.2%

24.5%

%/range

-

9.1%

17.5%

27.3%
37.8%
8.4%
0-7
79.7%
62.9%
49.7%
9.1%
7.7%
5.6%
3.5%
1.4%
-
60.1%
11.2%
25.2%
2.8%
0.7%
-
51.0%
16.1%
28.7%
2.8%
1.4%
-
8.4%
14.7%
53.8%
11.9%
11.2%
-
28.7%
64.3%
7.0%
0.0%
0.0%

%/range

0-6
76.7%
65.1%
54.7%
54.7%

54.7%

37.2%

46.5%

7.0%

-

12.8%

23.3%

25.6%

32.6%

5.8%

%/range

-

46.0%

12.6%

41.4%

0.0%

0.0%

-

44.8%

12.6%

37.9%

3.4%

0.0%

-

5.8%

15.1%

53.5%

15.1%

10.5%

-

45.3%

12.8%

38.4%

3.5%

0.0%
