

**Supplementary Table 1. Frequency of answers of parents of CD children at ICIS items.**

Items	Frequency dimension			Concerns dimension		
	Never	Sometimes	Often	Never	Sometimes	Often
<b>The impact of the illness and its treatment</b>						
1. Because of my child's illness he may stop breathing	62	0	0	58	4	0
<b>2. There is a risk he may injure himself</b>	<b>22</b>	<b>38</b>	<b>2</b>	<b>24</b>	<b>28</b>	<b>10</b>
3. There is a risk he may be brain damaged or even died	62	0	0	62	0	0
4. The medication my child takes makes him less alert	62	0	0	62	0	0
5. The medication makes	62	0	0	62	0	0
<b>The impact on the growth and the child's adaptation</b>						
<b>6. My child is more moody because of his illness</b>	<b>12</b>	<b>44</b>	<b>6</b>	<b>14</b>	<b>34</b>	<b>14</b>
7. He is shy and more easily embarrassed	20	36	6	32	26	4
<b>8. Because of my child's illness. He is teased and bullied</b>	<b>24</b>	<b>38</b>	<b>0</b>	<b>30</b>	<b>18</b>	<b>14</b>
9. Because of my child's illness, he has few friends	56	6	0	56	2	4
10. Because of my child's illness, he has few interests	62	0	0	60	0	2
11. Because of my child's illness, my child has special problems with reading or maths	62	0	0	60	0	2
12. My child is less clever because of his illness	62	0	0	62	0	0
13. My child may not find a job when he leaves school	52	10	0	52	8	2
14. My child may take to take medication for years	62	0	0	60	0	2
15. My child may not marry or have a family	48	14	0	54	6	2
<b>The impact on the parents</b>						
16. My child make a fuss about taking his medicine	60	2	0	60	0	2
17. Because of my child's illness, it is difficult for him to use public transport	62	0	0	60	0	2
18. He is less able to care for himself	22	38	2	24	30	8
19. It is difficult to explain my child's illness to others	12	46	4	26	28	8
<b>20. It is difficult to explain my child's illness to him</b>	<b>10</b>	<b>32</b>	<b>20</b>	<b>14</b>	<b>14</b>	<b>34</b>
<b>The impact on the family</b>						
21. Because of his illness my child must be more closely watched	18	34	10	22	34	6

than other children						
22. It is difficult to give my other children enough attention	44	18	0	48	12	2
23. My child's illness limits what his brothers and sister can do	46	14	2	46	16	0
24. We have to restrict our holiday	16	42	4	30	28	4
25. His illness means we have fewer friends round	52	8	2	54	6	2
26. My child's illness limits how often we go out as a family	18	40	4	32	26	4
27. We have more arguments at home	58	4	0	56	2	4
28. We go out less often in the evenings as a couples	24	38	0	42	16	4
29. My child is more difficult to manage because of his illness	20	40	2	26	26	10
30. Because of his illness we turn down opportunities at work	58	4	0	58	4	0

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