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Table SI- Main issues collected during the parent interviews

Impact of the disease on social life and leisure

- The organization of leisure activities, vacations
- School absenteeism
- Teasing at school, the look of others
- Find the words to explain to others
- Lack of understanding from the community (family, friends)
- Couple problems
- Eating habits
- Lassitude of daily care, fatigue related to the care
- Emotional relationships
- Odor (nose care), epistaxis

Projection into the future

- Parents' concerns about their sick child's future
- Difficulties in choosing a profession
- Isolation

Constraint of the disease on outside travel and outdoor activities

- The practice of a sport activity

Financial burden of the disease

- Expenses related to illness not covered by health insurance

Acceptance of the disease

- Guilt
- Anxieties related to the transmission of the gene, -anxiety related to the genetic status of the siblings
- The risk for the next child and pregnancy
- Management of consultations and medical appointments (stress, frustration)
- Difficulty in finding childcare, administrative procedures
- Fear of hyperthermia, sorting out the symptoms related to the disease and those that are not
- Dental pain, getting your child to accept dentures, finding dentists
- Dressing
- Choosing therapeutic strategies (dental: bone grafts, implants...)

Relation with siblings

- Brother/sister relationships (jealousy, shame)

Table SII. Intrinsic value associated to the factors:

We obtain 5 relatively coherent dimensions:

1. Impact of the disease on social life and leisure (questions 1, 3, 5, 12, 13, 14, and 19 of the final questionnaire)
2. Projection into the future (questions 6, 7, 8, 11, and 17 of the final questionnaire)
3. Constraint of the disease on outside travel and outdoor activities (questions 2, 4 and 10 of the final questionnaire)
4. Financial burden of the disease (questions 15 and 16 of the final questionnaire)
5. Acceptance of the disease (questions 9 and 18 of the final questionnaire)

Since the 6th dimension contains only one variable, the associated item is removed: "Our child's illness makes it difficult to relate to his/her brothers or sisters". Furthermore, the item "My child needs more attention than other children depending on the season" is correlated with dimension 2 and dimension 3 with a slightly stronger correlation for dimension 3. Nevertheless, we propose to associate it with dimension 2 because it includes a temporal dimension. The dimensions are not hierarchized.

	Intrinsic Value	Difference	Ratio	Cumulated
1	7,38	5,22	0,37	0,37
2	2,16	0,41	0,11	0,48
3	1,75	0,38	0,09	0,56
4	1,37	0,04	0,07	0,63
5	1,33	0,10	0,07	0,70
6	1,23	0,23	0,06	0,76

Table III. Standardized regression coefficients from the final rotated factor pattern

Questions	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
1- I/We give up on certain leisure activities because of my/our child's illness	0.840	0.146	0.174	0.214	0.038
2- My/Our child's illness makes eating out complicated (restaurant, family)	0.837	0.146	0.136	0.087	0.303
3- My/Our child's eating difficulties affect my/our social life	0.811	0.088	0.028	0.131	0.190
4- I/We choose where to go on vacation based on my/our child's illness	0.805	0.027	0.141	0.258	-0.214
5- My/Our child's dental problems force me/us to exclude certain foods	0.662	0.415	-0.127	-0.110	0.168
6- My/Our child's illness has made me/us want to quit my/our job(s)	0.642	0.390	0.282	0.087	0.211
7- I/We fear for my/our child's future because of his/her illness	0.093	0.802	0.272	-0.033	0.141
8- Complications related to our child's illness worry me/us	0.227	0.693	0.117	0.315	0.232
9- I/We feel lost when faced with the symptoms of my/our child's illness	0.268	0.681	0.277	-0.076	0.038
10- My/Our child's illness has disrupted my/our life	0.231	0.552	-0.085	0.260	0.482
11- My/Our child's future career worries me/us	0.139	0.488	0.181	0.427	0.183
12- Each time I/we go to the hospital, I/we don't feel good the next day	0.009	0.115	0.869	0.254	0.114
13- Each time I/we go to the hospital, I/we don't feel good the day before	0.162	0.218	0.739	0.179	0.191
14- It takes a long time to get my/our child ready each morning because of his/her illness	0.169	0.165	0.715	0.068	0.054
15- I/We allocate part of my/our household budget to my/our child's care	0.125	-0.012	0.224	0.873	0.111
16- I/We have less money to spend because of the non-reimbursed costs associated with my/our child's illness	0.224	0.105	0.185	0.844	0.193
17- My/Our child needs more attention than other children depending on the season	0.139	0.464	0.107	0.507	-0.256
18- It is hard to get my/our child to accept dental care related to his/her illness	0.335	0.033	0.279	0.073	0.824
19- It is hard for me/us to see my/our child being teased because of his/her illness	0.036	0.342	0.157	0.149	0.728

Table SIV. Cronbach's alpha coefficient

Dimension	Cronbach's alpha coefficient	
	Raw	Standardized
Global	0.908175	0.909738
Dimension 1	0.898123	0.901095
Dimension 2	0.799621	0.811852
Dimension 3	0.786387	0.787381
Dimension 4	0.891534	0.895393
Dimension 5	0.766585	0.767083

Table SV. Correlations between the different questionnaires

PGWBI, Psychological General Well Being Index ; MCS, Mental Composit Score of SF12 ; PCS, Physical Composit Score of SF12

External Score	ED Score and components	N	ρ	CI 95%	P-value
PGWBI	Global ED score	50	-0.441	[-0.641 ; -0.185]	0.001
PGWBI	1st dimension	50	-0.317	[-0.547 ; -0.042]	0.025
PGWBI	2nd dimension	50	-0.428	[-0.631 ; -0.170]	0.002
PGWBI	3rd dimension	50	-0.350	[-0.573 ; -0.080]	0.012
PGWBI	4th dimension	50	-0.291	[-0.527 ; -0.014]	0.040
PGWBI	5th dimension	50	-0.227	[-0.475 ; 0.055]	0.113
PCS	Global ED score	41	-0.257	[-0.523 ; 0.055]	0.105
PCS	1st dimension	41	-0.238	[-0.508 ; 0.075]	0.135
PCS	2nd dimension	41	-0.074	[-0.373 ; 0.239]	0.647
PCS	3rd dimension	41	-0.164	[-0.449 ; 0.152]	0.309
PCS	4th dimension	41	-0.200	[-0.478 ; 0.115]	0.211
PCS	5th dimension	41	-0.294	[-0.551 ; 0.015]	0.062
MCS	Global ED score	41	-0.529	[-0.720 ; -0.265]	<.001
MCS	1st dimension	41	-0.320	[-0.572 ; -0.014]	0.041
MCS	2nd dimension	41	-0.459	[-0.672 ; -0.176]	0.002
MCS	3rd dimension	41	-0.408	[-0.636 ; -0.115]	0.008
MCS	4th dimension	41	-0.435	[-0.655 ; -0.147]	0.004
MCS	5th dimension	41	-0.449	[-0.665 ; -0.164]	0.003