

Scale	Subscale	Time of measurement	Group 1 (%)	Group 2 (%)	Total (%)	
CVS		T0-T1	9.7	10.6	10.1	
		T0-T2	4.2	9.1	6.5	
PIP	Total score frequency	T0-T1	2.8	3.0	2.9	
		T0-T2	2.8	1.5	2.2	
	Total score difficulty	T0-T1	1.4	1.5	1.4	
		T0-T2	0.0	0.0	0.0	
MFI	General fatigue	T0-T1	6.9	12.1	9.4	
		T0-T2	11.1	7.6	9.4	
	Physical fatigue	T0-T1	8.3	9.1	8.7	
		T0-T2	8.3	4.5	6.5	
	Mental fatigue	T0-T1	12.5	9.1	10.9	
		T0-T2	12.5	7.6	10.1	
	Reduction in motivation	T0-T1	13.9	16.7	15.2	
		T0-T2	11.1	4.5	8.0	
	Reduction in activity	T0-T1	12.5	6.1	9.4	
		T0-T2	8.3	4.5	6.5	
	PEPPI		T0-T1	33.3	48.5	40.6
			T0-T2	30.6	19.7	25.4
FaMM	Child's daily care	T0-T1	9.7	16.7	13.0	
		T0-T2	5.6	4.5	5.1	
	Condition management ability	T0-T1	5.6	12.1	8.7	
		T0-T2	5.6	4.5	5.1	
	Condition management effort	T0-T1	4.2	10.6	7.2	
		T0-T2	8.3	7.6	8.0	
	Family life difficulty	T0-T1	2.8	12.1	7.2	
		T0-T2	2.8	1.5	2.2	
	View on condition impact	T0-T1	6.9	9.1	8.0	
		T0-T2	1.4	3.0	2.2	
	Parental mutuality	T0-T1	12.5	9.1	10.9	
		T0-T2	5.6	7.6	6.5	