

Supplementary Table S1. CHQ-PF50 scores

CHQ-PF50 Scores	SJIA Patients (n=60)* mean \pm SD	CHQ Normative Data mean \pm SD
Global Health (GGH)	67.4 \pm 26.9	-
Physical Functioning (PF)	76.1 \pm 31.5	96.1 \pm 13.9
Role/Social Limitations - Emotional/Behavioural (REB)	79.3 \pm 30.3	92.5 \pm 18.6
Role/Social Limitations - Physical (RP)	76.9 \pm 34.9	93.6 \pm 18.6
Bodily Pain/Discomfort (BP)	73.2 \pm 26.6	81.7 \pm 19.0
Behavior (BE)	74.6 \pm 19.7	75.6 \pm 16.7
Global Behaviour (GBE)	72.3 \pm 25.4	-
Mental Health (MH)	73.6 \pm 16.1	78.5 \pm 13.2
Self-Esteem (SE)	69.3 \pm 22.0	79.8 \pm 17.5
General Health Perceptions (GH)	48.0 \pm 22.3	73.0 \pm 17.3
Change in Health (CH)	69.2 \pm 33.3	-
Parental Impact - Emotional (PE)	59.7 \pm 28.6	80.3 \pm 19.1
Parental Impact - Time (PT)	72.6 \pm 28.9	87.8 \pm 19.9
Family Activities (FA)	68.6 \pm 29.1	89.7 \pm 18.6
Family Cohesion (FC)	71.8 \pm 19.2	72.3 \pm 21.6
Physical Summary (PhS)	40.0 \pm 18.2	53.0 \pm 8.8
Psychosocial Summary (PsS)	46.6 \pm 11.3	51.2 \pm 9.1

*One caregiver did not complete the CHQ-PF50.

Normative values taken from a sample U.S. population of 391 children aged 5-18 (mean 11.5) years (30). -0.5 SD of the normative mean represents a clinically meaningful moderate effect size and -0.8 SD of the normative mean represents a clinically important large effect size (27).

Supplementary Table S2. SF36v2 scores.

SF-36v2 Scores	SJIA Caregivers (n=60)* mean \pm SD	SF-36 CHQ Normative Data mean \pm SD
Physical Functioning (PF)	53.6 \pm 6.6	50.0 \pm 10.0
Role Physical (RP)	50.7 \pm 8.5	50.0 \pm 10.0
Bodily Pain (BP)	52.3 \pm 10.5	50.0 \pm 10.0
General Health (GH)	52.1 \pm 9.9	50.0 \pm 10.0
Vitality (VT)	49.4 \pm 8.9	50.0 \pm 10.0
Social Functioning (SF)	49.2 \pm 9.3	50.0 \pm 10.0
Role Emotional (RE)	46.9 \pm 11.3	50.0 \pm 10.0
Mental Health (MH)	48.0 \pm 9.9	50.0 \pm 10.0
Physical Component (PCS)	54.1 \pm 8.1	50.0 \pm 10.0
Mental Component (MCS)	46.2 \pm 10.7	50.0 \pm 10.0

*One CAN caregiver completed the SF-36v2 after it had already been scored by the developers.

Normative values taken from a sample U.S. population (23).

Minimum clinically important effect size -0.3 SDs for MCS, PF, RP, BP, SF and MH, -0.2 SDs for PCS, GH and VT, and -0.4 SDs for RE (23).

Supplementary Table S3. SJIA caregiver stress.

Frequent high causes of SJIA caregiver stress*	SJIA Caregivers n (%) [N]*
Worrying about the long-term impact of their child's SJIA	27 (45) [60]
Feeling uncertain about the future of their child, their family and themselves, due to their child's SJIA	16 (28) [57]
Feeling unsure about their child's ability to become fully independent as an adult	15 (27) [56]
Feeling helpless about their child's SJIA	13 (24) [55]
Knowing their child is in pain due to SJIA or its treatments	12 (23) [52]
Feeling uncertain about their child's ability to get a job in the future	8 (14) [57]
Inability to attend to the needs of other family members, due to their child's SJIA	7 (13) [54]
Taking their child with SJIA to appointments for administration of drug therapy	5 (12) [41]
Making decisions about medical care or medications for their child with SJIA	5 (10) [48]
Missing important events in the lives of their family members or close friends, due to their child's SJIA	4 (8) [52]
Taking their child with SJIA to appointments with the SJIA specialist	3 (6) [47]
Feeling confused about medical information regarding their child's SJIA	2 (4) [53]
Feeling like they know more about SJIA than their child's healthcare providers	1 (2) [46]

* "How often..." was assessed on a five-point scale from "1 - Never" to "5 - Very often". "How stressful..." was assessed on a five-point scale from "1 - Not at all" to "5 - Extremely". Caregivers are reported who answered "4 - Often" or "5 - Very often" and "4 - Very much" or "5 - Extremely". Factors are listed in descending order of stressfulness.