

Table 3. Summary of included studies using instruments other than the World Health Organization Quality of Life Instrument-Brief Version.

Author and publication date, country, setting, study period	Sample size, study design, instrument	Age of children with DS, mean ± SD and/or range in years	Age of caregivers, mean ± SD or mode (no., %) or median ± SD and/or range in years; gender/sex (F/M), no. %	Comparison group	Highest domain OR biggest difference, ^a score (SD)	Lowest domain OR lowest difference, ^a score (SD)	Total score
Cetin 2017, ³⁵ Turkey, not specified	37, cross-sectional study, SF-36	Mean ± SD: 7.9 ± 3.5	Mean ± SD: 40.1 ± 6.1 F: 37, 100% M: 0, 0%	NA	Physical: 15.2	Mental: 12.5	130.5
Bourke 2008, ³⁶ Australia, 2004 to 2005	250, cross-sectional study, SF-12	Mean: 11.9	Mean: 44.4 F: 250, 100% M: 0, 0%	NA	Physical: 50.2	Mental: 45.2	NA
Darla 2020, ³⁸ India, not specified	102, cross-sectional study, PedsQL FIM	Range: 1–15	Mode: 35–39 (38, 37.25%) F: 51, 50% M: 51, 50%	NA	Cognitive function: 71.67	Worry: 57.33	NA
Rozensztrauch 2023, ³⁹ Poland, January 2022 to December 2022	53, cross-sectional study, PedsQL FIM	Mean ± SD: 6.48 ± 4.56 Range: 2–18	NA	NA	Cognitive function: 64.53 (24.42) Family relationship: 62.03 (24.49)	Worry: 41.98 (20.95) Daily activities: 44.97 (23.87)	57.51 (17.56)
Foley 2014, ⁴¹ Australia, 2009	289, cross-sectional study, BCFQOL	Range: 16–30	Range: 37–66 and older F: 150, 52% M: 139, 48%	NA	Physical/material well-being: 4.19	Emotional well-being: 3.49	NA
Brown 2006, ⁴² Canada, not specified	33, cross sectional study, FQOL	Range: 3–13	Mean (mothers): 38–40 Mean (fathers): 41–45	Typically developing children	^a Leisure and enjoyment of life (0.821)	Support from disability related services (0.300)	NA
Marchal 2013, ²¹ Netherlands, 1999 to 2001	98, cross sectional study, TAAQOL	Mean ± SD: 7.1 ± 0.6	Median ± SD: 41.3 ± 4.4 Range 32.4–51.9 F: 84, 86% M: 14, 14%	NA	Cognitive function (F=11.57)	Vitality (F=6.60)	NA
Marchal 2016, ²² Netherlands, 2012 to 2013	124, cross sectional study, TAAQOL	Range: 11–13	Mothers, mean ± SD: 45.9 ± 4.2 Fathers, mean ± SD: 47.8 ± 5.4 F: 80, 65.5% M: 44, 35.5%	NA	Fine motor function Mother 96.3 (9.2) Father 98.6 (7.7)	Vitality (57.2)	NA

BCFQOL: Beach Center Family Quality of Life; FQOL: Family Quality of Life; NA: Not applicable/not available; IQR: interquartile range; PedsQL FIM: Pediatric Quality of Life Inventory Family Impact Module; SD: standard deviation; SF-12: 12-Item Short Form Survey; SF 36: 36-Item Short Form Survey; TAAQOL: TNO-AZL Questionnaire for Adult's Health Related Quality of Life; TNO-AZL: The Netherlands Organization for Applied Scientific Research Academical Medical Center

^a The differences in individual QOL domain values between the control group and DS group of family caregivers (if applicable).