

Supplementary Table 1. Items in the short questionnaires and corresponding scales on the QoL-DSD.

Parent self-report			
16 Items on short version (Short PSR)	Corresponding scales on long version (Long PSR)	<i>n</i>	<i>r</i>
• I have enough information about my child's condition to make decisions about his/her care	Decision Making	21	0.50
• Fitting your child's care for his/her condition into your usual routines or daily activities	Role Functioning & Family Activities	24	0.23
• I am confident my child's gender was identified correctly	Gender Concerns	24	0.05
• My child's condition affects how often I go out socially	Social Functioning	24	0.37
• I feel happy	Emotional Functioning	24	0.71
• I feel concerned my child will have social problems, like being teased about his/her condition	Future Concerns	24	0.70
• I worry about my child's future relationships (e.g., dating, marriage)			
• I feel comfortable talking with my child about his/her condition	Talking to Others	24	0.72
• I worry about talking to others about my child's condition because of how they might react			
• Making sure your child receives his/her medications for the condition when he/she is away from you (e.g., at school or daycare)	Medications	5	0.74
• During the surgery	Surgery	13	0.60
• Not knowing what to expect at the visit	Doctor's Visits	24	0.89
• Managing your child's behaviour during the visit			
• Receiving your child's diagnosis	Earliest Experiences	24	0.76
• I am concerned about how my child's genitals look	Clinical Items	24	0.80
• I worry I could have another child with the same condition			
Parent proxy-report			
7 Items on short version (Short PPR)	Corresponding scales on long version (Long PPR)	<i>n</i>	<i>r</i>
• Due to his/her condition, my child experiences physical pain when urinating	Physical Functioning	19	0.34
• My child's condition affects his/her activities (e.g., play dates, swimming, sports)			
• My child feels different from other children of the same gender due to his/her condition	Gender Concerns	5	n/a
• My child has concerns about going to a public restroom because of his/her condition	Socio-Emotional Functioning	9	0.56
• My child has more difficulty being away from parents than other children his/her age			
• Having doctor's visits (e.g., physical exams)	Medical Care	19	0.57
• Taking medication for his/her condition	Clinical Item	5	0.25

Note. *n*'s vary as some children were not taking medication, had not had previous surgery or were too young for responses to be provided. *r*; Pearson's correlation coefficient.