Do Children with Cerebral Palsy & Their Parents Agree in Their Ratings of the Child's Quality of Life?



Summary

Quality of life is defined as an individual's personal perception of their well-being and general satisfaction with life. Some aspects of quality of life attributes are objective and observable, such as their physical health and general functioning, whereas other attributes are subjective, and reflect how a person feels about their life. The authors evaluated quality of life of children of school-age with cerebral palsy, by having the children complete the self-report measure. They also asked a parent to complete a proxy-report of the same items about their perceptions regarding their child's quality of life. There was very good agreement between children and their parents on physical well-being attributes, and moderate (less strong, but significant) agreement on psychosocial aspects of well-being. Parents' ratings were generally lower than their child's ratings. Agreement between parent and child was stronger if the child was: older (closer to 12 than 6 years of age), male, had higher social competency, better functional abilities, and fewer emotional symptoms. Overall, there was very good agreement suggesting that parents may be used as a proxy reporter in the situation when children are unable to complete questionnaires themselves. However, disparities exist, therefore children themselves should complete quality of life questionnaires whenever feasible, so as to gain their own perspectives.

What families and practitioners should know

- A parent's view of their child's quality of life is similar to the child's own perceptions of their quality of life. Agreement is strongest for physical health and functioning but is less strong for social-emotional health.
- Parents can be used as a proxy-respondent on a quality of life questionnaire for their child with cerebral palsy, if the child is unable to complete the questionnaire themselves.
- If the child can complete the questionnaire, it is preferable that they provide their own point of view.

Reference

Majnemer, A., Shevell, M., Law, M., Poulin, C. & Rosenbaum, P. (2008). Reliability in the ratings of quality of life between parents and their children of school age with cerebral palsy. Quality of Life Research, 17, 1163-1171