

PARENTS' EXPRESSIONS OF CONCERNS AND HOPES FOR THE FUTURE AND CONCOMITANT ASSESSMENTS OF DISABILITY IN THEIR CHILDREN

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Background: To ask parents to freely express their concerns and hopes for the future in their children with disability and assess their children's disability as well as to analyse these data for consistency.

Materials & Methods: Parents of 162 children with spina bifida, spinal muscular atrophy, muscular disorders, cerebral palsy, visual impairment, hearing impairment, mental disability or disability following brain tumours were asked to freely express their concerns and hopes for the future and to assess disability in their own children by employing a set of 26 ICF-CY body function (b) codes and activity and participation (d) codes. A grounded theory approach was employed to systematise parents' expressions of concerns and hopes; then, parents scored on a 5-step qualitative Likert scale. Identically, parents assessed their children's disability using the ICF-CY 5-step Likert qualifier scale.

Results: Altogether, 119 parents freely expressed their concerns and hopes. Of those, 101 also assessed their child's disability using the 26 ICF-CY codes. A total of 475 expressions of concerns and hopes (issues) were expressed and categorized into 34 areas of concern and hopes (subsections). The most frequent issues involved education and understanding, goodwill and communication between parents and community support. Qualitative data on both 5-step qualifier scales showed good reliability. Rasch analysis maps on concerns and hopes for children as well as on ICF-CY assessment demonstrated good alignment and a clinically relevant progression from least to most disabled children.

Conclusions: Parents can express valid and reliable data on their concerns and hopes for the future and can reliably assess disability in their own children.

Reference: Illum NO, Bonderup M, Gradel KO. Parents' expressions of concerns and hopes for the future and their concomitant assessments of disability in their children. *Clinical Medicine Insights: Pediatrics* 2018;12:1-13