
Aim - The aim of this study was to describe stress in the parents of children with cerebral palsy and investigate associations with very high stress.

Method - A cross-sectional survey was conducted of parents of 818 children aged 8 to 12 years from nine regions in Europe. Families were eligible to participate if they were living in one of the specified geographic areas. Parental stress was captured using the Parenting Stress Index Short Form, which has 36 items and takes 10 minutes to complete. Parents rate items on a 5-point Likert scale, with higher scores indicating higher stress. The Short Form yields scores on three subscales and a Total Stress score. A trained research associate administered the questionnaire in the child’s home and visits lasted 90 to 120 minutes. All data collected were reported by parents unless otherwise stated.

Results - The Total Stress score on the Parenting Stress Index was dichotomized into scores of less than 99 or 99 or more, the latter indicating 'very high' stress. Most respondents were mothers (94%), and 26% reported very high stress levels. The parents of children with communication impairment had higher odds for very high stress (odds ratio [OR] 1.9; 95% confidence interval [CI] 1.2–3.0) than those whose child had no such impairment; the parents of children with moderate or severe pain had higher odds for very high stress (OR 1.7 [95% CI 1.1–2.4] and 2.5 [95% CI 1.5–4.3] respectively) than those whose child had no pain; and the parents of children with an intellectual impairment had higher odds for very high stress (OR 1.8; 95% CI 1.2–2.9) than those whose child had none. There was no association between very high stress and motor impairment. The subscales ‘parent–child dysfunctional interaction’ and ‘difficult child’ contributed most to the Total Stress score.

Interpretation - Parents of children with communication difficulties, intellectual impairment, or pain are at very high risk of stress. The final model explained 12% of the observed variation in very high stress.