Quality of life in young people with cerebral palsy

A study of cross-sectional and longitudinal European data found that young people with mild or moderate cerebral palsy mostly had similar quality of life to young people in the general population, but had less social support from friends and peers.

Overview: Cerebral palsy encompasses a number of lifelong neurological conditions that affect movement and coordination (NHS Choices 2014). The main symptoms of cerebral palsy are: muscle stiffness or floppiness; muscle weakness; random and uncontrolled body movements; and difficulties with balance and coordination.

Previous evidence suggests that children with cerebral palsy report similar quality of life (QoL) to children in the general population (Bjornson et al. 2008). However, the evidence on QoL among young people with cerebral palsy is inconsistent.

Current advice: The NICE guideline on spasticity in children and young people with non-progressive brain disorders recommends that the child or young person and their parents or carers should be offered contact details of patient organisations that can provide support, befriending, counselling, information and advocacy.

NICE is currently preparing a guideline on diagnosis and management of cerebral palsy (anticipated publication date October 2016).

The NICE pathway on spasticity in children and young people brings together all related NICE guidance and associated products on the condition in a set of interactive topic-based diagrams.

New evidence: Colver et al. (2015) used data from the SPARCLE study to assess QoL in young people with cerebral palsy. The SPARCLE study recruited 818 children with cerebral palsy from population-based registers in 7 European countries, including the UK. Participants were interviewed at home aged 8–12 years (SPARCLE1) and aged 13–17 years (SPARCLE2). Participants self-reported their QoL, using the 10-domain KIDSCREEN questionnaire (scale 0–100 for each domain), and how frequently they experienced pain each week.

This analysis used cross-sectional data from 431 young people who were able to self-report their QoL at 13–17 years. Most participants had no or moderate motor limitations. A total of 355 of these young people reported QoL at both 8–12 years and 13–17 years and were included in longitudinal analyses.
Young people with cerebral palsy were compared with matched young people in the general population.

The cross-sectional analysis found that young people with cerebral palsy had no worse QoL than young people in the general population on 9 of the 10 domains assessed. QoL was worse among young people with cerebral palsy in terms of social support available from friends and peers (mean difference compared with the general population=–2.7, 95% confidence interval –4.3 to –1.4).

Pain was the main factor that affected QoL among young people with cerebral palsy. Impairment type and severity also had an impact on QoL; for example, seizures in the previous year were associated with reduced QoL for moods and emotions and impaired walking ability was associated with reduced autonomy.

In the longitudinal analyses, QoL decreased between childhood and adolescence for 5 of the 10 domains assessed, but the changes in mean score on each domain were small at less than 3 points. QoL as young people was affected by high parenting stress in childhood and childhood psychological difficulties.

Limitations of this analysis include that children and young people with severe learning difficulties who could not self-report were excluded. In addition, children with cerebral palsy and the general population controls were recruited differently, and around a third of children with cerebral palsy targeted for inclusion in the study did not take part.

Commentary by Mr Mathew David Sewell, Consultant Spine Deformity Surgeon, The James Cook University Hospital, South Tees Hospitals NHS Foundation Trust, Middlesbrough:

“QoL is defined by the World Health Organization (WHO) as ‘the individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns’. The WHO considers QoL and participation, the latter defined as involvement in life situations, as key outcome measures to assess following intervention for children with impairments.

“Data obtained through the SPARCLE studies suggest that participation is more affected in children with cerebral palsy than QoL. SPARCLE1 reported that children with cerebral palsy aged between 8–12 years had lower participation than children in the general population (Fauconnier et al. 2009). Those with more severe impairments had lower participation across most domains. The picture is quite different for QoL, which was less influenced by impairments and was broadly similar between children with cerebral palsy and the general population (Dickinson et al. 2007).

“The current study provides further evidence to suggest that young people with cerebral palsy have at least equivalent QoL to those in the general population, and that frequency of pain is the most significant factor associated with lower QoL. Child psychological difficulties and parenting stress were identified as modifiable risk factors associated with lower QoL. The only domain in which adolescents with cerebral palsy had lower QoL than the general population was in the domain of social support and peer relationships.

“The large sample size provides a compelling argument that these results are valid. However, the high non-response rate and exclusion of children not able to self-report (mostly the more severely affected children) represents a selection bias that limits the study’s validity and generalisability.

“As practising clinicians, we should ask young people with cerebral palsy about pain, psychological stressors and parenting stresses, as targeted intervention in these areas could improve QoL. Young people with cerebral palsy may need particular help developing and maintaining peer relationships. This could be through facilitating greater participation (for example, helping the young person attend school and therefore make friends). It should be remembered that all children and young people with cerebral palsy are different, and each requires individualised management plans that seek to maximise QoL and participation across all domains.”
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