



Family adaptation to cerebral palsy in adolescents: A European multicenter study



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ABSTRACT

Background and aim: Factors promoting family adaptation to child's disability are poorly studied together. The aim of the study was to describe the family adaptation to disability and to identify determinants associated with using a global theoretical model.

Materials and methods: 286 families of teenagers [13–17 years] with cerebral palsy (CP) from 4 European disability registers were included and visited at home. Face to face interviews were performed in order to measure parental distress, perceived impact in various dimensions of family life, family resources and stressors. Relationships were modelled with structural equations.

Results: 31.8% of parents living with an adolescent with CP showed clinically significant high stress requiring professional assistance. The main stressors were the level of motor impairment and behavioural disorders in adolescent. A good family functioning was the best protective factor. Respite in care and a parents' positive attitude were significantly related to less parental distress. Material support, socioeconomical level, marital status or parental qualifications did not appear to be significant protector factors.

Conclusions: Particular attention must be paid not only on physical condition but also on adolescent psychological problems to improve family adaptation. Families at risk of experiencing severe distress should be targeted early and proactive caregiver interventions on the whole family should be performed.

What this paper adds: Family is a dynamic system: facing disability, it tries to recover its balance with available resources and its perception of the situation. Literature highlights potential stressors and protecting factors that could affect the disabled child's family adaptation but few papers study a global model including most of these factors. This study validated a global theoretical model of family adaptation to disability at adolescence. It identified behaviour disorders and motor impairment level as main stressors, family functioning as the largest protecting factors, and equipment and financial support as non significant protective factors.

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Abbreviations: CFI, Comparative Fit Index; CP, Cerebral palsy; FICD+4, Revised Family Impact of Childhood Disability; PSI, Parenting Stress Index; RMSEA, Root Mean Square Error of Approximation; SD, Standard Deviation; SEM, Structural Equation Modelling; TLI, Tucker-Lewis Fit Index; WLSMV, Weight least-squares means and variance adjusted.

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Introduction

The birth of a disabled child has a long-term family impact, which has already been described (Guyard, Fauconnier, Mermet, & Cans, 2010; Rentinck, Ketelaar, Jongmans, & Gorter, 2007; Skinner & Weisner, 2007; Vermaes, Gerris, & Janssens, 2007). Seven dimensions of family life that may be influenced have been identified: constraints on time (Curran, Sharples, White, & Knapp, 2001; Saigal, Burrows, Stoskopf, Rosenbaum, & Streiner, 2000; Sen & Yurtsever, 2007), employment (Brehaut et al., 2004; Porterfield, 2002; Wallander & Venters, 1995), financial consequences (Brehaut et al., 2004; Curran et al., 2001; McCubbin, 1989), positive modifications of social relationships (Brehaut et al., 2004; Florian & Findler, 2001; Saigal et al., 2000) or negative modifications of social relationships (Green, 2003; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Sen & Yurtsever, 2007) or intrafamilial relationships (Florian & Findler, 2001; Joesch & Smith, 1997; Pirila et al., 2005; Weisner, Matheson, Coots, & Bernheimer, 2004), physical impact on caregivers (Brehaut et al., 2004; Eker & Tuzun, 2004; Lach et al., 2009) and caregiver's psychological wellbeing, with more depressive symptoms and anxiousness in parents of children with disabilities (Brehaut et al., 2004; Manuel, Naughton, Balkrishnan, Paterson Smith, & Koman, 2003; Wallander & Venters, 1995) than in other parents.

Some families adjust better than others, but factors promoting this adaptation are poorly known and seldom studied together. In this complex situation, some outcomes can explain others and may be mediated by external factors (Guyard et al., 2010; Rentinck et al., 2007; Skinner & Weisner, 2007; Summers et al., 2005). Family stress theories provide a dynamic view in which stress is explained as a process of adaptation (Lazarus & Folkman, 1984). The ABCX model of adaption from McCubbin (H. McCubbin & Patterson, 1983) offers an easy-to-understand concept of this process of adaptation: families dealing with a stressful situation experience a pile-up of stressors (A) across time. Two mediating blocks of factors influence the level of family adaptation (X): the resources available and used by the family (B) and the family's perception of the situation (C). Both of these mediators are influenced by primary stressors (A) and contribute to adaptation (X). Adaptive resources (B) can be internal or external to the family system. The perceived impact (C) refers to the family's appraisal of how consistently resources (B) match needs (A).

Here we suggest a model of family adaptation, establishing our hypotheses (Fig. 1), using factors identified in literature and based on the ABCX model.

The present study aimed to describe the family adaptation to disability based on a conceptual model related to the ABCX model in order to identify determinants associated with the level of family adaptation in families living with an adolescent with cerebral palsy (CP).

2. Materials and methods

2.1. Participants and procedure

The population targeted was families of adolescents with CP, ranging from 13 to 17 years of age at the time of the interview, living in the counties of Cork (Ireland), Haute-Garonne and Isere (France), and in Eastern Denmark. Families were recruited from a population-based registry. This research is a part of the Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE) including nine areas in Europe (further details on the sample procedure are available elsewhere (Colver, 2006)). This sample contained 286 families, visited at home between January 2009 and April 2010.

We obtained ethical approval, or a statement that only registration was required, as appropriate to each country. We obtained signed consent from all parents and from young people in the cases where it was possible

2.2. Measures

All the questionnaires used in SPARCLE were validated. Questionnaires used for studying the family adaptation to disability are described in Table 1.

2.3. Statistical method

The data were analyzed using the structural equation method. The main outcome was the score of parental distress from the subscale of the Parenting Stress Index (PSI) (Abidin, 1995). Three measurement models (Fig. 2) were defined to assess latent concepts.

- Among stressors (A), the level of impairment was described through two latent variables: motor impairment and associated impairments. The first had three reflective indicators: walking ability, bimanual skills and difficulty feeding. The second impairment latent variable grouped three other items: cognitive impairment, communication disorders and epileptic seizures.
- Among resources (B), the positive attitude of parents coping with the disability was assessed through five items from the Family Impact of Childhood Disability – revised (FICD+4) identified previously (Guyard et al., 2012).
- The negatively perceived impact (C) was described through five latent constructs expressing the negative perception on social relationships, constraints on time, work life, financial consequences, and healthcare costs for family members. Ten

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