

Well-being of Parents of Children with Autism Spectrum Disorder or Developmental Coordination Disorder: Cross-Cultural and Cross-disorder Comparative Studies

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Abstract : Context: Nowadays, supporting parents of children with autism spectrum disorder (ASD) and helping them adjust to their child's condition represents a core clinical and scientific necessity and is encouraged by the French National Strategy for Autism (2018). In France, ASD remains a challenging condition, causing distress, segregation and social stigma to concerned family members concerned by this handicap. The literature highlights that neurodevelopmental disorders in children, such as ASD, influence parental well-being. This impact could be different according to parents' culture and the child's particular disorder manifestation, such as developmental coordination disorder (DCD), for instance. Objectives: This present study aims to explore parental stress, anxiety and depressive symptoms, as well as the quality of life in parents of children with ASD or DCD, as well as the explicit individual, psychosocial and cultural factors of parental well-being. Methods: Participants will be recruited through diagnostic centers, child and specialized adolescent units, and organizations representing families with ASD and DCD. Our sample will include five groups of 150 parents: four groups of parents having children with ASD - one living in France, one in the US, one in Canada and the other in Lebanon - and one group of French parents of children with DCD. Self-evaluation measures will be filled directly by parents in order to measure parental stress, anxiety and depressive symptoms, quality of life, coping and emotional regulation strategies, internalized stigma, perceived social support, the child's problem behaviors severity, as well as motor coordination deficits in children with ASD and DCD. A sociodemographic questionnaire will help collect additional useful data regarding participants and their children. Individual and semi-structured research interviews will be conducted to complete quantitative data by further exploring participants' distinct experiences related to parenting a child with a neurodevelopmental disorder. An interview grid, specially designed for the needs of this study, will strengthen the comparison between the experiences of parents of children with ASD with those of parents of children with DCD. It will also help investigate cultural differences regarding parent support policies in the context of raising a child with ASD. Moreover, interviews will help clarify the link between certain research variables (behavioral differences between ASD and DCD, family leisure activities, family and children's extracurricular life, etc.) and parental well-being. Research perspectives: Results of this study will provide a more holistic understanding of the roles of individual, psychosocial and cultural variables related to parental well-being. Thus, this study will help direct the implementation of support services offered to families of children with neurodevelopmental disorders (ASD and DCD). Also, the implications of this study are essential in order to guide families through changes related to public policies assisting neurodevelopmental disorders and other disabilities. The between-group comparison (ASD and DCD) is also expected to help clarify the origins of all the different challenges encountered by those families. Hence, it will be interesting to investigate whether complications perceived by parents are more likely to arise from child-symptom severity, or from the lack of support obtained from health and educational systems.

Keywords : Autism spectrum disorder, cross-cultural, cross-disorder, developmental coordination delay, well-being

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