

POSTER

‘What hurts and worries us’: The meaning of autism from the perspective of the family

From the perspective of all the family members involved, what is the *experience* of autism? And how do family members make sense of this experience? The prevalence of young people diagnosed with Autism Spectrum Disorder (ASD) has increased significantly in Chile, with most studies investigating its impact on the nuclear family - leaving the impact and influence of this phenomena on the extended family to be overlooked. This qualitative study explores the whole family experience of a child diagnosed with ASD, from the perspective of parents, siblings, grandparents and uncles. A case study was conducted using interpretative phenomenological analysis (IPA): data collection consisted of semi-structured interviews with six family members from Temuco (Chile). Findings illustrate the experience of family members associated with the diagnosis of autism (e.g. uncertainty about the future; frustration) as well as the unexpected emotional and social demands (e.g. acceptance; adaptation; discrimination) linked to the care of an autistic child. Two major themes are presented in this poster: 1) Facing the diagnosis: what hurts and worries the family; and 2) the challenges and demands of caring for a child with autism. The study contributes to understanding the meaning-making process within the family as it emerges from their day-to-day living, and the reciprocal influences on one another that family members have regarding their experience of caring for a child with autism.

The implications of this work for practice:

The study vividly illustrates the emotional and relational strain experienced by family members when a child is diagnosed with ASD. It particularly highlights the experience of family members outside the immediate nuclear family, who become equally involved in the care and support of the child. The findings suggest issues that can be explored for therapeutic gain.

The implications of this work for research:

There is a need to broaden our understanding of the experience of extended family members who are actively involved in caring for a child with ASD in the Chilean context. It becomes clear that further research is necessary on the psychotherapeutic processes of the family involvement - this in consideration of the significant emotional impact that the diagnosis has, and the tendency of the family to avoid communication of these difficulties.