Researching the quality of life of people with ASD and their families - insights from a large-sample mixed-mode study

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Abstract

The quality of life and the psychological well-being of people with autism spectrum disorder (ASD) and their families have been in the focus of research and have received growing attention in the last decade. Several studies from various countries/cultures have confirmed that parents of persons with autism experience lower quality of life than parents of typically developing individuals. It has also been shown, however, that there is a positive relationship between parents’ quality of life and the quality of services received by their children. A better understanding of factors and causal interactions/transactions that determine quality of life and psychological well-being in families with children with autism, therefore, is highly desirable for planning individual interventions as well as for designing strategies and services on institutional, community and national levels.

At the centre of the talk there lies a summary of the key results and conclusions from a large-sample mixed-mode study among parents with children with ASD, conducted by our research group in Hungary, in 2017-2018. A quantitative on-line survey, based mainly on standard data collecting tools, was aimed at gaining data primarily on parental quality of life, parents’ personal sense of coherence, parental sense of competence, and coping strategies. We collected data from a total of 527 parents of children with autism, and from 326 parents of typically developing children. Our qualitative study, based on parental interviews (n = 36), was aimed at a better understanding of the results of the quantitative study and gaining deeper insights into individual patterns and life-span tendencies. Key results of the quantitative study are in line with the international literature: e.g., lower overall quality of life, sense of coherence and parental sense of competence characterised the sample with ASD child. The qualitative study has complemented these results by providing insights about how parents perceive and judge the services their children receive; about factors parents perceive as supporting and having positive impact, and their ideas on ways of improving services and personal/family well-being; etc.

Another focus of the talk is an overview of the key methodological issues having arisen in the process of designing and conducting the study, analysing data and interpreting findings. These issues included, among others, finding an optimal coordination between quantitative and qualitative study elements, reaching potential respondents with very low socio-economic status, forming an optimal interviewer profile, and identifying a specific interpretation framework for the qualitative data.

The talk is motivated by our conviction that quality of life and psychological well-being in families remain key issues in understanding autism in its broad context and in developing adequate services and strategies; and that improvements in research methodologies can significantly contribute to these processes.