

Neurodivergent and neurotypical parents' experiences of early parental guidance and post-guidance needs

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Introduction

Early parental guidance is considered important for parents of autistic children.

Prior studies on parental guidance experiences have reported both positive and negative experiences, such as parental empowerment but also increased parental stress (e.g., Jurek et al., 2022).

Previous studies highlight the need to tailor interventions to the needs of each family (e.g., Schuck et al., 2022).

It is therefore crucial to understand the guidance needs of different kind of families.

Limited research has focused on similarities and differences in the experiences and needs of neurodivergent and neurotypical parents.

Aims

This qualitative interview study examines the 1) experiences of early parental guidance and 2) post-guidance needs of neurodivergent and neurotypical parents of toddlers with autistic traits in Finland.

Methods

A semi-structured interview protocol was designed in collaboration with two autistic mothers.

The interviewed parents had previously participated in an early pre-diagnostic parental guidance on supporting social interaction.

Twelve randomly selected families participated. One or both parents of five families reported being neurodivergent.

Mothers were interviewed in seven, fathers in one, and both the parents in four interviews.

The interviews were conducted either face-to-face, via videoconferencing or telephone, depending on parental preferences.

The mean interview duration was 53 minutes.

The study drew on phenomenographic approach. The analysis was conducted using qualitative data-driven content analysis.

Results

The analysis identified five themes regarding parents' experiences of guidance.



The analysis further revealed three themes regarding parents' post-guidance needs.



Regarding differences between the neurodivergent and neurotypical parents, neurodivergent parents expressed their own neurodivergence facilitating their understanding toward their child.

“ --- I see similar things in her what I myself have so through that I feel I have quite a good understanding of her.”

Neurodivergent parents also expressed a connection between their neurodivergent traits and managing everyday life with an influence on their parenting.

“ --- how to say to a child that mom cannot deal with being touched right now --- ? All the senses are very much on the limits all the time.”

Conclusions

Similar themes emerged in the interviews with both neurodivergent and neurotypical parents. The differences had to do with neurodivergent parents stressing their own divergence as influencing their parenting.

The future development of parental guidance should be increasingly sensitive to the needs of both neurodivergent and neurotypical families.

Our future work focuses on co-designing neuroaffirmative parental guidance together with the autistic communities.

