

Having a Second Child, When Your First has Autism

A Qualitative Study of Parental Experiences

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Background

- Around 20% of infants who have an older sibling with Autism Spectrum Disorder (ASD) are later diagnosed with autism themselves (Ozonoff et al., 2011)
 - A further 20–30% develop broader developmental difficulties (Messinger et al., 2013)
- Diagnosis of a child with autism has short- and long-term impacts on family functioning, including on family planning (Navot et.al, 2016)
- No research on lived experience of parents who have had a child diagnosed with autism, and gone on to have another child



Objectives

- **Objective:** This study sought to better understand the impact of the diagnosis of a child with autism on parents, and how this impacts the experiences of parents around the conception, pregnancy and early developmental period of a subsequent child.
- Aims:
 - Inform a intervention currently being developed
 - More broadly inform clinicians and researchers



Participants

- Two groups of 10:
 - Mothers who had a child diagnosed with an autism and went on to have another child (focal group) and
 - Mothers of two or more children (comparison)
- Demographics:
 - Two parent households
 - Two-three children in each family, youngest under 6
 - IRSAD codes 1-5 in each group (mean; focal group=3.1, control=3.8)
 - Index of Relative Socio-economic Advantage and Disadvantage (IRSAD)
 - Older siblings with autism diagnosis aged 2-8 at diagnosis, varied presentation



Methods

- In-depth interviews with parents
- A minimal number of broad, data-generating questions were asked as recommended in phenomenology (Brod, Tesler, & Christensen, 2009; van Manen, 2016)
 - Allowed participants to speak about the experiences that were most salient to them
- Interviews lasted between 1-2 hours and were transcribed verbatim.

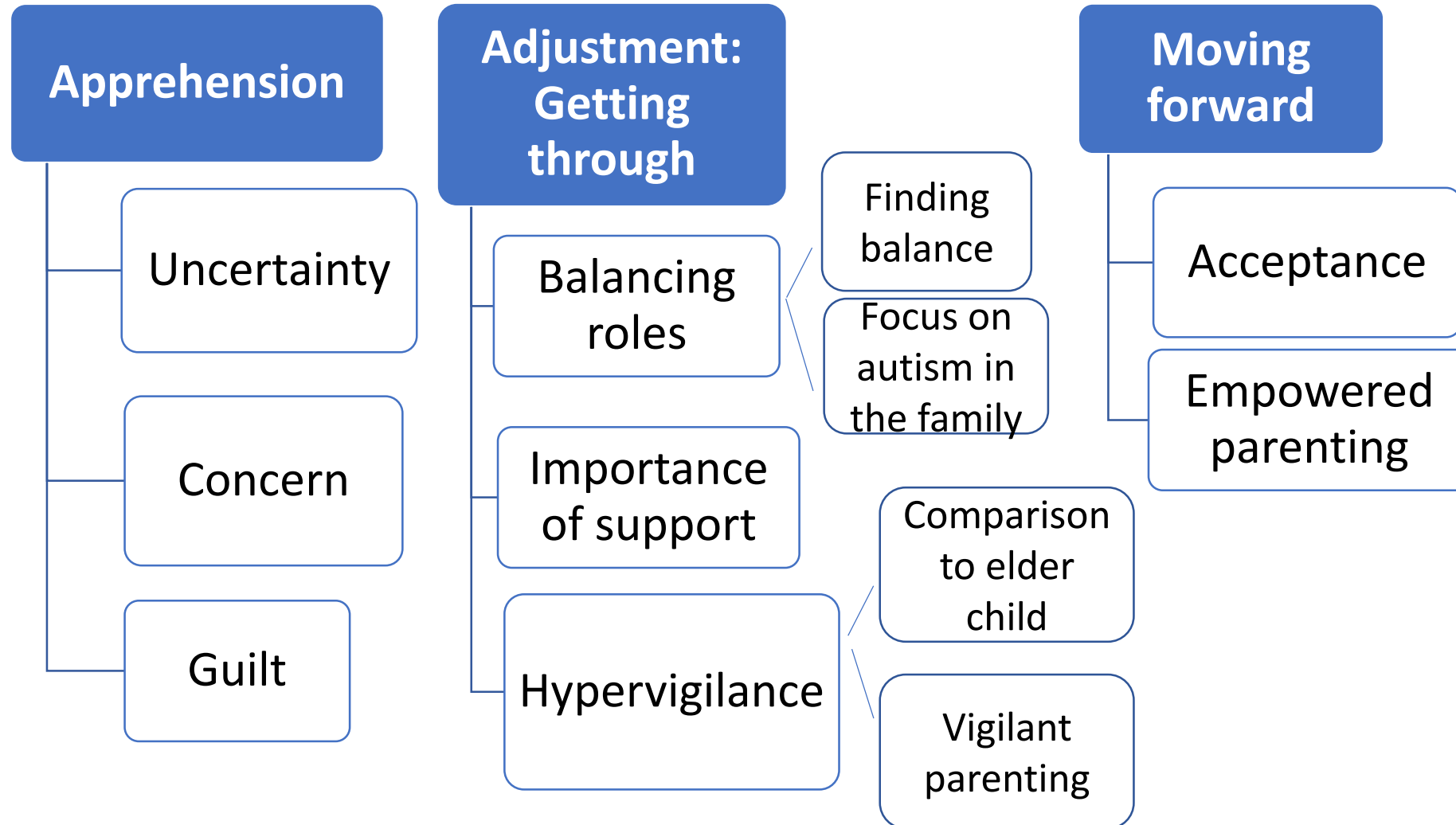


Data Analysis

- Data analysis was concurrent with data collection, and involved a thematic analysis of the data conducted using through the following steps:
 1. Transcripts were reviewed in the entirety
 2. Data coding was performed using NVivo (QSR International Pty Ltd. Version 11, 2016)
 3. Themes and sub-themes were developed through placing similar codes together for continuous comparison
 4. Themes were re-evaluated as new data became available (Strauss & Corbin, 1990).

Recruitment of 10 parents (mothers) in each group reached thematic saturation.

Results: focal group





Theme: Apprehension

Uncertainty:

- “There’s a gap [between our kids] because we weren’t going to have another one, purely...because we weren’t sure if we’d be able to cope.”
- “I think we found out about 12 weeks [gestation that] we were pregnant with a boy and then basically spent the rest of the pregnancy worrying and stressing what was going to happen next.”

Concern:

- “I mean, I love him to pieces and I wouldn't swap him, but I do wish maybe life is going to be easier for him than it is for my eldest.”
- “Okay, well, there’s so many red flags for this child, but no one can help me.”

Guilt:

- “Parents will blame themselves, as you do. What else do you do? It’s my genes... so the parental guilt is kind of huge.”
- “I know it has nothing to do with it but I felt like I did all that I could but there’s this...guilt or fear of what if my child has this because I didn’t do enough.”



Theme: Adjustment; Getting through

Balancing roles:

Finding balance:

- “.. it’s not that I put that pressure on myself, but they’d both have their needs and I really had to ...just figure out how I could meet them both.”

Focus on autism in the family:

- “As a mother with a new baby, your focus for caring for the newborn is secondary to maintaining support for the child with autism.”
- “I felt because (First child) had this disability that he required more attention than what (Second child) does.”
- “I still kind of feel that the bottom line is that our whole home now is about autism and that’s how we parent.”



Theme: Adjustment; Getting through

Importance of support:

- “If I hadn’t had family around? Oh, I don’t reckon I would have coped.”
- “I probably wouldn’t have had another child [laughingly] if I didn’t have family around..”

Hypervigilance

Vigilant parenting

- “Is there anything that I can do while the baby is growing...”
- “But I have to admit... when we did hear it was a boy I did think straight away, “Okay, now I’ve got to really be on my game.”
- “I’m paying more attention to it. Like, I’m really looking at where his eyes are focussed, where his hands are focussed...only because I’m aware of it now ... of how important those things are.. they’re all indicators”

Comparison to older child

- “It did have an impact because every time he [younger child] had one of her [older child’s] behaviours or something ... was he copying, should I be worried..?”



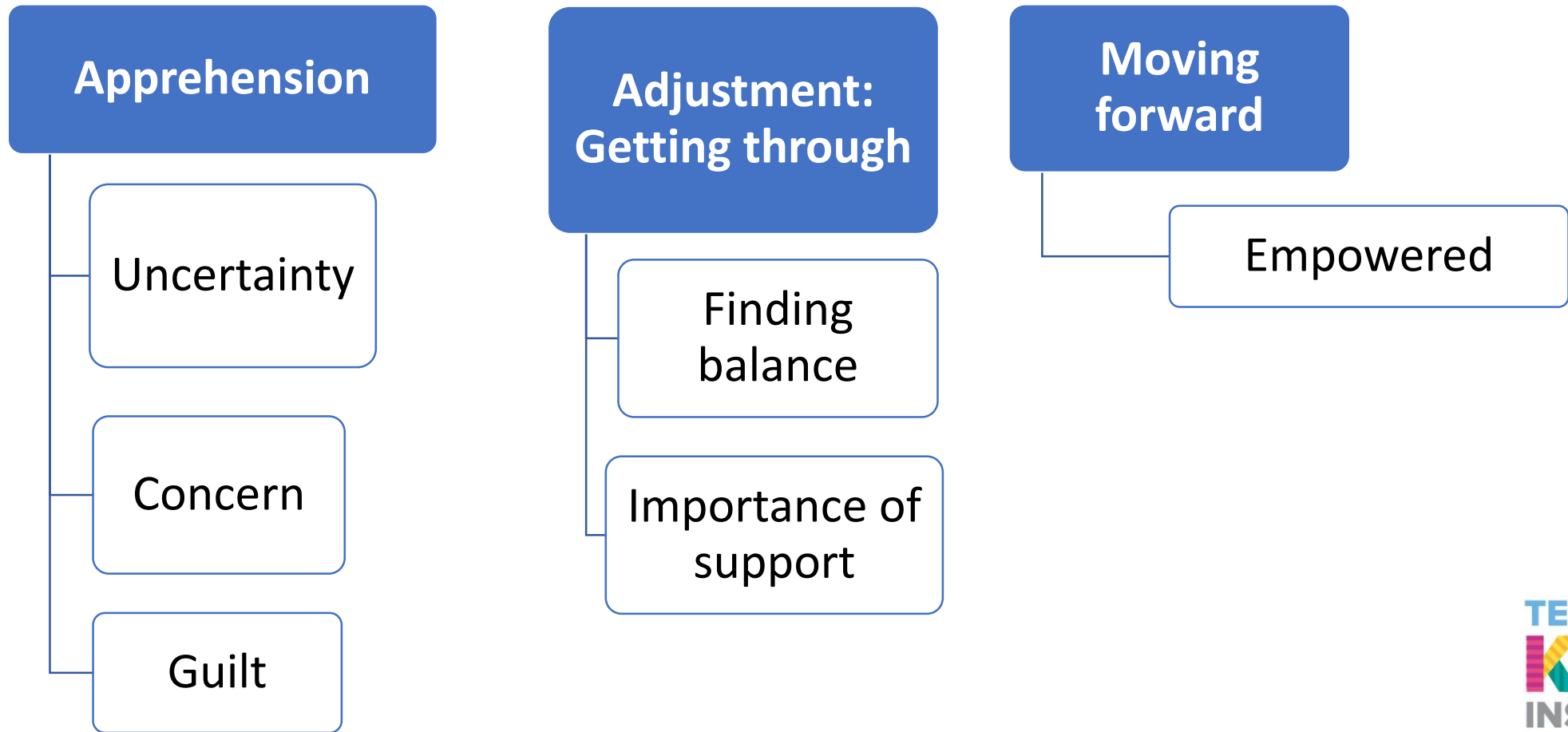
Moving forward

Subthemes:

- Acceptance:
 - “We said...“Are we prepared to have another child on the spectrum?” ...“Yes!” ...at the end of the day they’re all kids, they’re all special and unique in their own way and they’ve all got stuff. So that wasn’t a factor as in we did”
 - “I wouldn’t fear it... it’s what’s made our lives really amazing and really special”
- Empowered:
 - “If we’re going to go down this path, I know exactly where [and] how I was going to handle it.”
 - “...having (youngest child), ...however it’s going to go, we’re going to be ok with her.”



Results: control group





Differences between the groups

- Apprehension:
 - Guilt; expressed differently
 - Concern; less focussed on development in control group
- Adjustment/getting through:
 - Focus on autism in the family not expressed
 - Hypervigilance not expressed
- Moving forward
 - Acceptance not expressed



Implications

- The results of this study will be used to inform a parent-mediated intervention for infant siblings of children with autism
- Broad implications for clinicians and researchers working with the parents of children with autism
 - Improving understanding of the unique challenges faced by parents in this situation
 - Identifying opportunities in therapy or support for parents



Limitations and future directions

- Limitations:
 - Parent group only a subgroup of parents with a child with autism
 - Only maternal experiences
- Future directions
 - Broader groups of parents
 - Examination of the impact of additional factors



Conclusions

- Having another child, when you have had a child diagnosed with autism is a unique and multi-layered experience
- Important for researchers and clinicians to consider this experience when working with families in this situation
- The development of emotional, informational and practical supports could help empower families in this situation going forwards



Questions?





References

- Brod, M., Tesler, L. E., & Christensen, T. L. (2009). Qualitative research and content validity: developing best practices based on science and experience. *Quality of life Research*, 18(9), 1263.
- Messinger, D., Young, G. S., Ozonoff, S., Dobkins, K., Carter, A., Zwaigenbaum, L., . . . Sigman, M. (2013). Beyond autism: a baby siblings research consortium study of high-risk children at three years of age. *J Am Acad Child Adolesc Psychiatry*, 52(3), 300- 308.
- Navot, N., Jorgenson, A. G., Vander Stoep, A., Toth, K., & Webb, S. J. (2016). Family planning and family vision in mothers after diagnosis of a child with autism spectrum disorder. *Autism*, 20(5), 605-615.
- Ozonoff, S., Young, G. S., Carter, A., Messinger, D., Yirmiya, N., Zwaigenbaum, L., . . . Dobkins, K. (2011). Recurrence risk for autism spectrum disorders: a Baby Siblings Research Consortium study. *Pediatrics*, 128(3), e488-e495.
- Strauss, A., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*: Sage Publications, Inc.
- van Manen, M. (2016). *Researching Lived Experience, Second Edition : Human Science for an Action Sensitive Pedagogy (2nd ed. ed.)*. Walnut Creek: Routledge.