



The Impact of Down syndrome on Parents and Neurotypical Siblings

Background

- Down syndrome** is the most common chromosomal disorder. Down syndrome can cause deficits in cognitive functioning and is often associated with health concerns, with varying severity. It may also present comorbidly with psychological disorders.
- Parents have described negative experiences and framing** surrounding the diagnosis and a lack of adequate support.
- Family members have reported atypical responsibility** in care and support for the individual with Down syndrome.
- Family members have also reported positive impacts:** overall, on familial relationships and on their own character.
- Most research focuses on parental experience**, with little considering both parent and sibling impact.

Selected references: Farkas, L., Cless, J., Cless, A., Nelson Goff, B., Bodine, E., & Edelman, A. (2018). The Ups and Downs of Down Syndrome: A Qualitative Study of Positive and Negative Parenting Experiences. *Journal Of Family Issues*, 40(4), 518-539. <https://doi.org/10.1177/0192513x18812192>

Skotko, B., Levine, S., & Goldstein, R. (2011). Having a brother or sister with Down syndrome: Perspectives from siblings. *American Journal Of Medical Genetics Part A*, 155(10), 2348-2359. <https://doi.org/10.1002/ajmg.a.34228>

Purpose

To explore how parents, siblings and overall family dynamics are impacted by having a child or sibling with Down syndrome.

Methods

- Used a **qualitative research design** in order to gain an in-depth insight into participant experiences and reflections.
- Conducted **individual semi-structured interviews**, enabling participants to speak freely without influence of others' accounts.
- Used **Interpretative Phenomenological Analysis**, allowing for detailed exploration of data. Sub-ordinate and super-ordinate themes were developed from examination of transcripts through a process of abstraction, whereby emergent themes were grouped by focus similarity.
- 11 adult participants:** 6 parents and 5 siblings of individuals with Down syndrome.

Results: 4 super-ordinate themes, 13 sub-ordinate themes

Super-ordinate themes	Sub-ordinate themes	Supporting quotations
View of diagnosis	<ul style="list-style-type: none"> -Learning of diagnosis -Co-morbid health concerns -Individual vs. diagnosis -Societal attitude 	<p><i>"It was horrendous. It was delivered really, really badly"</i></p> <p><i>"I think the biggest issue was that his heart ... So the Down syndrome really wasn't sort of the thing that was impacting us"</i></p> <p><i>"Down syndrome lives in each person in very different ways because that person is also an individual"</i></p> <p><i>"I also think there's been so much like positive like things from society"</i></p>
Additional considerations	<ul style="list-style-type: none"> -Additional needs -Role of carer -Considerations of the future 	<p><i>"She's an additional consideration"</i></p> <p><i>"I suppose she's [SIBLING] a bit of a mini carer for him"</i></p> <p><i>"So inevitably I am going to become her everything"</i></p>
Impact on the family	<ul style="list-style-type: none"> -Positive impact on the individual and family -Challenges to the family -Impact on familial relationships 	<p><i>"It's life enriching"</i></p> <p><i>"I felt like I was second best a lot in my childhood"</i></p> <p><i>"I think it's brought us together more"</i></p>
Experiences with support	<ul style="list-style-type: none"> -Support provisions -Healthcare -Education 	<p><i>"Everything is a fight"</i></p> <p><i>"Not handled in the best way and also there wasn't any information really, there wasn't any support at all"</i></p> <p><i>"To get her accepted as mainstream, that was quite a battle"</i></p>

Discussion

Key Findings	Implications	Future Research
<ul style="list-style-type: none"> -Parents viewed delivery and framing of diagnosis negatively. -Comorbid concerns or disorders were often described as the focus, or of more impact, than Down syndrome. -The individual with Down syndrome required additional considerations, accommodated by both parents and siblings. Participants spoke of increased responsibilities and care-taking roles, especially for siblings. -A 'fight' for support was described, with inadequate support particularly during transitional periods. -Whilst parents and siblings described common themes, for some, perspective or experience of impact differed dependent on the familial role. -Although there was an awareness of the consequences of supporting an individual with Down syndrome, the impact of having a child or sibling with Down syndrome was described as overwhelmingly positive, for parents, siblings and the family unit. 	<ul style="list-style-type: none"> -The overwhelming positive impact of having a child or siblings described may contest the potential negative framing others can have. This finding may be valuable in the optimistic adjustment of families and informing practitioner understanding. -Participant experiences of inadequate support and the negative ramifications of such suggests it is paramount improvements be made in support for not only individuals with Down syndrome, but also their families. -Suggests the importance of clinicians' understanding the presentation and impact of comorbid disorders in individuals with Down syndrome. 	<ul style="list-style-type: none"> -Further understanding into the presentation and impact comorbid disorders can have on family members. -Explore the impact on siblings across age range, as effect may develop or change. <p>Limitation: Participants were able to view questions prior to interview, atypical in IPA methodology. However, this was deemed appropriate to reduce participant anxiety and facilitate recruitment.</p>