Exploring the Lived Experience of Growing Up with an Autistic Sibling

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INTRODUCTION

- Families raising children with autism experience added responsibilities and challenges.
- The added attention required to support an autistic child may affect family dynamics and the experience of non-autistic siblings.

OBJECTIVE

Explore the impact of having an autistic sibling on childhood and adult experiences, as well as identify future supports to better assist these individuals.

METHODS

- A qualitative phenomenological approach was used to explore lived experiences.
- Purposive sampling was used to recruit adult participants (n=44) between the ages of 18 and 49 who had an autistic sibling.
- Recruited from research projects in California, Georgia, and Utah, US
  - Participants lived in multiple states around the US
- A total of seven focus groups and five interviews held via Zoom.
- Conversations recorded, transcribed verbatim, organized in MaxQDA qualitative software, and coded independently by a team of four non-autistic researchers, one who has an autistic sibling.

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The Sibling Paradox

"I realized a lot of things about my household were not typical. But if I had the chance to live it over again, I wouldn't change a thing."

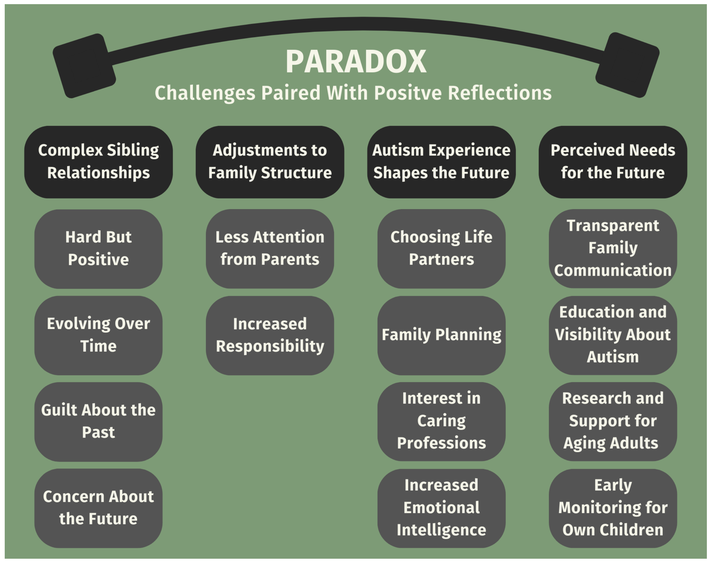
Increased Emotional Intelligence

"As far as relationships with other people, I do think having an autistic sibling does help with just understanding differences in people and how to accommodate for others as well."

Concern About the Future

"My whole life, I've seen that my mother doesn't have time outside of taking care of my sister full-time. She says a lot of the time that she feels like she's lost a lot of her identity as an individual person because she spent so much of her time and all of her energy staying up all night and doing everything for my sister. I think that would be a fear of mine."

RESULTS



Challenges

- Communication with sibling
- Sibling's challenging behavior
- Less time and attention for own needs
- Family stress about care and navigating support services

Positive Reflections

- Strong love for my sibling and bonding over shared interests
- Developed more emotional intelligence, compassion for others
- Appreciation for unique family culture

Concerns for the Future

- Stress of providing care for their adult siblings
- Potential stress of providing care for a future autistic child
- Lack of support services for autistic adults beyond high school

IMPLICATIONS

- Adults who grew up with an autistic sibling highlight the need for education about autism for themselves and society to better understand their siblings.
- They value transparent communication about the interaction of autism within their family systems.
- They ask for more research and services for their adult siblings and to support their own future families.

ACKNOWLEDGEMENTS

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