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Family Caregiver Perceptions of Social Interactions of Persons with Autism Spectrum Disorder

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Introduction

- •1 in 54 children has Autism Spectrum Disorder (ASD)
- •ASD is a lifelong neurodevelopmental disorder characterized by challenges in communication and social interaction
- Parenting a child with ASD is associated with high stress, depression, anxiety, and reduced quality of life
- Social support is protective against stress, anxiety, and depression
- •Research Question:

How do family caregivers of persons with ASD experiencing behavioral and/or psychological challenges perceive social interactions within the family and in the community?

Method

- Basic qualitative case study methodology
- •Sample: single family caregiver to a person with ASD
- •Setting: Suburban community dwelling family in Northern California
- •Data collection: single semi-structured interview protocol, 7-day journal of social interactions, field notes
- •Data analysis: 6 phase Thematic analysis (Braun & Clarke)
- •Theoretical framework: Sense of Coherence
- •Institutional Review Board: Approval #2020081 MU, application #260202, University of Missouri

Results

Thematic Map of a Family Caregiver's Experiences and Meanings



Walking this Journey is Learning and Growing

- Celebrating milestone or little victory with joy
- Patience with many roles and losses
- Experiencing stigma, and shame

Keeping the World Open is Managing

- New experiences
- Family bonds
- Hope for the future

Witnessing his Challenges is Observing

- Communication challenges
- Self-harm
- Public meltdowns

Discussion

- Positive social support appeared to contribute to family caregivers' perception of family functioning
- Findings of affiliate /courtesy stigmatization related to behaviors like vocalizations and meltdowns confirms the extant literature
- Future research to understand middle and older adult family caregiver's stigmatization may inform design of tailored intervention programs and catalyze public funding to prevent social isolation and loneliness
- Limitations of study: convenience sample, single case study, and non-diverse sample

Collaboration and Networking

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