



A qualitative study exploring
the lived experiences and
coping strategies of families
living with autism spectrum
disorder

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Autism Spectrum Disorder (ASD)

- › Neurological disorder: social behaviour, communication, restricted or repetitive patterns of behaviour (CDC, 2018)
- › South Africa: estimated 2% prevalence (World Autism Day Awareness, 2018).

Research Questions

1. What are the lived experiences of families living with ASD in KZN?
2. What coping strategies are utilised by parents and siblings of children with ASD?



Methodology

- › Qualitative, phenomenological study
- › Seven families: Mothers (n=7), Fathers (n=1)
Siblings (n=6)
- › Data collection: semi-structured interviews
- › Data thematically analysed according to Braun & Clarke (2006)
- › Ethical principles



Lived experiences of parents and siblings

› ***Diagnostic Process*** → ***protracted and stressful***

Parents: health professionals, time frames

Siblings: stressful times

Cultural: poor parenting, bad behaviour

Religious: demon possession, witchcraft

Poor support following diagnosis



› ***Impact of ASD → focus on the child***

Relationships: spousal; parents and typical children

Parents: burden of care, responsibility, negative emotions, employment changes

Future concerns for the CASD: attainment of life roles, adolescence

Stigma: decreased awareness and understanding

Positive attainment, personal growth, personality traits



› **Challenges**

Behavioural: most challenging

Communication: parents accepted and acknowledged

siblings dismayed

Socialisation: communication, negative reactions of public,
triggers and sensitivities of the CASD

Resource limitations: education, healthcare



Coping with ASD

- › Lack of professional support
- › **Coping strategies:** trial & error, internet, social support networks, family discussions, spirituality
- › **For CASD:** distraction, giving in to demands, routines
- › **Siblings:** distraction, walking away
- › **Parents:** immersion in work, acceptance



The way forward....

- › Create awareness
- › Training curricula of teachers
- › Advocacy
- › Opportunities for support
- › Health professionals