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)


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