

PSYCHOLOGICAL DISTRESS AND COPING STRATEGIES AMONG CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS (ASD)

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BACKGROUND

Psychological distress refers to a range of emotions or mental suffering that can result from stress, anxiety, depression or other mental health issues. In the researchers experience, Occupational Therapists in Kenya encounter cases of psychological distress among the caregivers of children with Autism Spectrum Disorder (ASD). According to Ntre *et al.* (2022), having a child with Autism may have a strong impact on the family, especially on mothers, who are usually the primary caregivers of children with ASD.

PROBLEM STATEMENT
Parents of children with ASD report more mental health problems compared to parents of children with typical development or other developmental disabilities. Parental coping strategies play a significant role when parents have to overcome stressful situations during the child's development (Dykens *et al.*, 2014 & Dardas *et al.*, 2024). Caregivers of children with ASD experience psychological distress due to challenges associated with caregiving, impacting their overall well-being and quality of life. Despite the prevalence of these issues, there is lack of comprehensive understanding regarding the psychological distress they experience and the specific coping strategies they employ found in the literature.

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PICO QUESTION

Based on the problems identified, the PICO question is as follows:

- In caregivers of children with ASD, how do coping strategies affect their psychological distress level and improve their mental wellbeing compared with those not using specific strategies?

OBJECTIVES

- To assess the psychological distress experienced by caregivers of children with ASD.
- To examine the coping strategies utilized by caregivers to manage stress.
- To provide evidence-based recommendations for interventions and support programs aimed at improving the mental health and coping skills of caregivers.
- To identify gaps in the existing literature and propose areas for future research on caregiver well-being and support mechanisms.



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METHODS

A qualitative descriptive study design (Doyle, 2020) will be used in this research to explore and describe the experiences of psychological distress and coping strategies among caregivers of children with ASD.

Structured and semi-structured interview questions will be used to guide interviews aimed at capturing personal experiences and narratives regarding distress and coping strategies. Interviews will be recorded, de-identified and transcribed.

Sampling and Recruitment Method: Purposive sampling to identify families raising a young child (2 to 8 years old) with ASD will be recruited through collaborating with clinics, and support groups focused on ASD, utilizing whatsapp platforms dedicated to Autism support.

Setting: This study will be conducted in clinical setting; using clinical spaces within Kijabe Hospital.

Sample size: The researchers will interview approximately 9 caregivers of children with ASD, or until data saturation is met.

Inclusion criteria: Caregivers of children diagnosed with ASD.

Exclusion criteria: Caregivers of children with a primary diagnosis of a disability other than ASD (e.g., intellectual disabilities, down syndrome) will be excluded to ensure that the study focuses specifically on the experiences related to ASD.

Ethical approval will be obtained from the Institutional Scientific and Ethical Review Committee of Kijabe Hospital prior to the commencement of the study.

DATA ANALYSIS

Qualitative Analysis: Thematic analysis by coding the data collected through interviews will be used to identify common themes related to distress and coping strategies.

Quantitative Analysis: Demographic information will be analyzed and reported using descriptive statistics. This analysis will include key variables such as age of the caregiver, relationship to the child, age of the child, gender of the child, marital status of the caregiver and occupation.

DISSEMINATION OF FINDINGS

- Research findings will be presented at the annual KOTA (Kenya Occupational Therapists Association) scientific conference. The main findings will be presented, focusing on levels of psychological distress and common coping strategies identified among caregivers. Implications for occupational therapy practice will be discussed, emphasizing how these findings can inform interventions and support strategies for caregivers.
- Findings will also be shared through workshops and interactive sessions for caregivers and professionals.

EXPECTED OUTCOMES

- Comprehensive understanding of the psychological distress in caregivers.
- Identification of effective coping strategies.
- Recommendations for targetted support programs that address the challenges faced by caregivers, promoting resilience and better mental health outcomes.
- Identification of gaps in resources and support that caregivers feel they need, which can inform service provision and policy recommendation.

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References
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