

TITLE: AFFILIATE STIGMA EXPERIENCES AMONG CAREGIVERS OF CHILDREN WITH NEURODEVELOPMENTAL DISORDERS IN RURAL KILIFI AND NAIROBI'S INFORMAL SETTLEMENTS. A PHENOMENOLOGICAL QUALITATIVE STUDY.

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ABSTRACT

Background

Caregivers of children with neurodevelopmental disorders (NDDs) face multifaceted challenges, among which stigma—particularly affiliate stigma—is a major concern. Affiliate stigma occurs when caregivers internalize negative societal attitudes directed towards them due to their association with their children with developmental challenges. This internalized stigma may impact on the caregiver and child's mental health, overall wellbeing, and functioning. There is limited evidence on the lived experiences of affected caregivers, particularly in the African context. Exploring these experiences is critical in tailoring contextually appropriate support resources, which remain scarce in such settings.

Objective:

To explore affiliate stigma experiences, coping mechanisms, and interventional needs for caregivers of children with NDDs in rural Kilifi and Nairobi's informal settlements.

Methods:

A phenomenological qualitative study involving in-depth interviews with 35 caregivers purposively selected to represent: urban and rural settings; children of diverse age, gender, and NDD diagnosis including autism spectrum disorder, global developmental delays and intellectual disability, attention deficit/hyperactivity disorder, and epilepsy. A semi-structured interview guide was used to contextualize and explore affiliate stigma experiences. Interviews were audio-recorded, transcribed verbatim, and analyzed using a thematic approach and managed using NVivo software.

Results:

Findings revealed that caregivers experienced widespread stigma from multiple sources including family members, neighbors, community, healthcare providers, and learning

institutions. Stigma manifested as social rejection, judgement and discrimination, which led caregivers to internalize these negative experiences. The internalization of stigma resulted in feelings of shame, sadness, guilt and hopelessness. Social isolation and emotional burden were commonly reported, often resulting in diminished self-worth and a sense of being stuck in a life trajectory they lacked control for. This further led to avoidance in public settings, people, and social events due to feelings of embarrassment, discomfort with public scrutiny, or the challenges of managing their child's behavior. Sometimes, caregivers resort to concealing their child's condition through masking or by physically hiding their child. Compounding these experiences were systemic issues such as inadequate support services, lack of trained professionals, and absence of childcare support. These factors increased the caregiving burden and limited caregivers' participation in economic and community life, leading to perceived losses in status, identity, and future potential.

Conclusion:

This study highlights the profound psychological and social impact of affiliate stigma experienced by caregivers of children with NDDs in rural and urban Kenya. There is urgent need for stigma-reduction interventions, greater community education and advocacy, development of inclusive, culturally appropriate support systems, whilst recognizing the value of validating caregivers lived experiences. Addressing affiliate stigma is critical to improving the mental health outcomes for both caregivers and children with NDDs.

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