



MINISTRY OF HEALTH

Contribution ID: 145

Type: Oral Presentation

Building Resilience at the Margins: Psychosocial Needs and Family-Centered Mental Health Support for Youth Living with Sickle Cell Disease in Kenya

Keywords: Sickle Cell Disease, youth mental health, resilience, psychosocial support, family-centered care

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Background: Adolescents and young adults living with sickle cell disease (SCD) in Kenya experience layered psychosocial challenges that extend beyond the clinical symptoms of the illness. Their mental health is shaped by interactions across individual, interpersonal, and structural levels. This study explored these multi-level experiences to inform the design of culturally grounded, family-centered mental health interventions.

Methods: Guided by the socio-ecological model and community-based participatory research (CBPR) principles, we conducted 15 focus group discussions with adolescents (ages 10–25), caregivers, and healthcare providers at three public hospitals in urban, rural, and semi-urban Kenya. Thematic analysis was used to identify needs and resilience strategies across ecological levels.

Results: At the individual level, adolescents reported emotional distress related to chronic pain, fear of early death, academic disruption, and challenges in identifying and communicating emotional needs. At the interpersonal level, participants highlighted strained family communication, caregiver emotional exhaustion, and peer isolation due to stigma. At the structural level, barriers included a lack of mental health training for healthcare providers, fragmented referral systems, and geographic inaccessibility of psychosocial services. Despite these challenges, resilience emerged through adaptive family routines, religious faith, peer solidarity, and goal setting. Caregivers and providers emphasized the importance of safe spaces for emotional expression, tools for disclosure and self-advocacy, and more integrated mental health care within chronic disease services.

Conclusion: Findings underscore the urgent need for multi-level, culturally sensitive psychosocial interventions for youth with chronic illness. Addressing adolescent mental health in the context of SCD requires coordinated efforts that strengthen individual coping, family support systems, and healthcare infrastructure.

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Track Classification: Securing the Future: Holistic Approach to Mental Health for Generations: Foundations of mental health: A focus on the family, children, and youth mental health