

Influence of gender norms in relation to child's quality of care: follow-up of families of children with SCD identified through NBS in Tanzania

Daima Bukini, Columba Mbekenga, Siana Nkya, Leonard Malasa, Sheryl McCurdy, Karim Manji, Julie Makani & Michael Parker

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Abstract

Introducing newborn screening (NBS) services for sickle cell disease (SCD) in Africa has been proven to be one of the most cost-effective approach to reducing morbidity and mortality associated with this condition. In view of this evidence, efforts have been made by countries in Africa where SCD prevalence is high to pilot NBS programmes and to strengthen comprehensive care services for SCD. While it is important to reap the benefits of NBS for SCD in Africa in terms of overall quantitative measures, it is also important to understand how certain social and cultural conditions may disproportionately influence the outcomes of screening for some groups. The aim of this study was to analyse the role of gender norms before and after NBS for SCD in Tanzania, and to assess how they influence the quality of care of diagnosed children. Using qualitative methods, we did in-depth interviews with families of children with SCD identified through the NBS services and focus group sessions with nurses working in neonatal and postnatal sections of regional referral hospitals in Dar es Salaam. By analysing the experiences of both the families and nurses, we were able to provide evidence on, firstly, the gendered relations that undergird childcare and, secondly, how those relations influence the quality of care the child may potentially receive. The results emphasize the importance of studying the social implications of SCD in Africa, especially with regard to improving the quality of care for patients with SCD in the region. We propose simple interventions, including gender-conscious health education and genetic counselling, which can help to improve the community understanding of genetic diseases while also reducing gender-related inequalities related to SCD care in Africa.