Understanding the burden of surgical congenital anomalies in Kenya: an international mixed-methods approach

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Background: Surgical congenital anomalies (CAs) are significant contributors to pediatric disability, affecting 6% of births worldwide. Children in low- and middle-income countries are particularly affected, experiencing an estimated 94% of the world’s serious birth defects. The multidimensional burden of CAs is a major public health problem and has yet to be appreciably addressed by health systems. Conducted through international partnership, the objective of this study was to examine the perceptions of caregivers and health professionals towards surgical congenital anomalies in Kenya to ultimately inform social policy and public health program development.

Methods: A cross-sectional mixed methods triangulation study was conducted in a community and hospital setting in Nairobi and Kijabe, Kenya between March and April 2012. Qualitative focus group discussions were held with health care professionals (n=46) and community caregivers (n=32). Quantitative data was collected through administration of a 5-point Likert survey (5=strongly agree) and a visual analogue scale derived from the EuroQol-5D instrument. Neurological, craniofacial, urological and gastrointestinal surgical conditions were examined. Iterative thematic analysis using NVivo V.10.0 and descriptive statistics using SPSS V.20.0 were conducted. Quantitative and qualitative data were collected and analyzed separately, and then integrated using an inductive comparative method.

Results: Elements of Kenyan children’s disability experience identified were stigmatizing perceptions impairing community integration, low self-esteem, lack of independent mobilization, and limited schooling and employment opportunities attributed to discriminatory practices. Caregivers reported abandonment by community and family, condemnatory attitudes faulting them for CAs, and barring from social services as barriers affecting their quality of life. Quantitative results indicated that neurological conditions were associated with the highest stigma (M=4.3, SD=1.1), while gastrointestinal defects affected socialization and ability to go to school to the greatest extent (M=4.4, SD=1.0 and M=4.1, SD=1.3 respectively). Final mixed method analysis revealed that stigmatizing attitudes were attributed to community beliefs perceiving CAs as supernatural curses, and translated into psychological distress in children and their caregivers.

Conclusion: Key factors associated with the burden of CAs for patients and their caregivers in Kenya were identified. Programs addressing the social determinants of the burden of CAs, particularly community stigma and discrimination, are lacking in current health services and are contributing to the disability of surgical conditions. This study highlights the need for Kenyan rural and urban health systems to go beyond the medical dimensions of illness by linking knowledge of social and cultural influences to the delivery of local health services and public health program planning.