Understanding the Burden of Surgical Congenital Anomalies in Kenya: An International Mixed-Methods Study

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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
- CAs have ranked in the top 15 leading causes of premature death and disability in sub-Saharan Africa
- As sub-Saharan Africa faces limited specialized surgical resources for repair of CAs, many infants are not treated and face lifelong disability
- The extent of disability is largely shaped by external environmental factors
- Given the complex multi-dimensionality of disability, measuring it is challenging

Objective

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 from March-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
  - Raters were asked to assess the impact of 15 prevalent CAs across 6 domains of living (stigma, capacity to pursue schooling, feeding capacity, socialization, toileting, and discrimination)
  - Using surgical expert opinion, the domains of living were modified from the Euro-Qol 5D Iterative thematic analysis using NVivo v.10 and descriptive statistics analysis using SPSS v.20 was conducted.

Results

Quantitative Findings

Quantitative results indicated that:

- Neurological conditions were associated with the highest stigma (4.3, SD=0.7) and discrimination (4.5, SD=0.3)
- Craniofacial defects exerted the highest impact on children’s feeding capacity (3.8, SD=0.6)
- Gastrointestinal defects affected socialization (4.4, SD=0.3), toileting capacity (4.6, SD=0.3) and capacity to pursue schooling (4.1, SD=0.5) to the greatest extent

The mean scores based on a 5-point Likert scale, with 0=strongly disagree and 5=strongly agree, for the domains of living are as follows:

- Stigma
- Feeding Capacity
- Capacity to Pursue Schooling

Results (cont’d)

Qualitative Findings

The major constructs of disability surrounding CAs that emerged were:

- Social: Family abandonment; barring from social gatherings
- Economic: Excluded from schooling and limited employment prospects
- Cultural: CAs attributed to supernatural punishment
- Psychological: Self-stigmatization; comparison to others; anger at self
- Personal Living: Limited independent mobilization and self-caring capabilities

Mixed-Methods Findings

Final mixed-method analysis revealed that:

- The highest burden of disease is exerted by neurological and gastrointestinal defects, which in turn impact the child and caregiver experience of disability through 5 major constructs
- Negative socio-cultural attitudes towards CAs as supernatural curses have resulted in limited infrastructure support systems for socioeconomic development and personal autonomy
- These attitudes have ultimately translated into ongoing psychological distress and impaired quality of life in children and their caregivers

Conclusions

Key themes associated with the burden of CAs in Kenya were identified. At present, health systems are not meeting the needs of children with CAs and their caregivers. It is therefore recommended that:

- Public health campaigns informing the public and health professionals about CAs be conducted
- Increased financial resources be targeted towards the repair of CAs exerting a high burden of disease
- Stronger policies addressing the 5 constructs of disability for severe CAs be adopted
- Further research into the effectiveness and feasibility of CA-focused health services and programs be explored.

This study highlights the need for Kenyan rural and urban health systems to go beyond the medical dimensions of illness by linking knowledge of the highly severe CAs and their impact of varying constructs of disability to the delivery of local health services and public health program planning.

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