Quality of life for families with spina bifida in Kenya

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SUMMARY Spina bifida (SB) affects children worldwide. Studies from developed nations have explored the impact of SB on the quality of life of children and their parents. However, there are no such studies available from developing countries. We have therefore undertaken to document the impact of the disability on the families of affected children in Kenya. A questionnaire was administered to 40 mothers and their children, who were receiving treatment for SB at our institution. The results of this study should indicate where community and governmental resources and educational efforts for the disabled should be directed.

Introduction

The International Classification of Functioning, Disability and Health (2001) defines health in terms of impairment, activity limitations and participation restrictions. Children with spina bifida (SB) are affected by each domain. The neurological level influences mobility, continence and the risk of infections, while hydrocephalus causes cognitive impairments. The chronic nature of SB can complicate parental resolution of grief and adaptation to the disability. Multiple factors can lead to social isolation, school attendance problems, difficulty securing employment and, ultimately, can affect the quality of life (QOL) of the child and their family.

Few studies exploring QOL in children or families affected by disability have been published from developing nations. The questionnaire included demographics, the presence of hydrocephalus, the need for clean intermittent catheterization (CIC) and QOL questions deemed appropriate for age and for the Kenyan setting. The neurological levels were obtained from the hospital charts.

Results

The sexes were evenly represented: mean age was four years (range 11 days–22 years). Hydrocephalus was present in 23 children, 18 of whom had a shunt. Recorded motor levels were 21% thoracic, 46% lumbar and 33% sacral. Of 19 children over 18 months of age, eight (42%) had urinary incontinence. CIC was practiced by 40% of the mothers. Half of mothers reported a great financial impact of the child’s disability. Most were married, with variable impact of the child on their marriage. Three marriages had broken down as a result of the child’s condition. Urinary incontinence had a negative impact on marriage (4.4/5 score for incontinent children versus 3.9 for continent, 5 being the worst). The use of CIC had a positive impact on the marriage (3.3/5 with CIC versus 4.2 without); neither of these differences reached statistical significance.

Only 17 of the mothers were taking folic acid provided free by our institutions – despite the majority knowing of its importance during pregnancy for the prevention of neural tube defects.

Only six found their community very helpful, while 15 had received no assistance at all. Seven reported being shunned; nine felt that they or their other children were cursed because of the birth of the disabled child. Seventeen reported that their spiritual life had been impacted by the child, in most cases positively. Thirty had been befriended by someone from their local church, but eight had received no support. Half the mothers knew of other families in their community with a disabled child.

Discussion

QOL may be determined more by a combination of functional loss and dependency than by the type of disability. Western studies have documented the social disadvantages associated with the loss of power and mobility, impaired bowel and bladder control and hydrocephalus – including a decreased opportunity for peer relationships, prolonged dependency on parents and decreased community acceptance. They suggest that QOL could be increased if mobility and bladder impairment were addressed; yet in Kenya, SB children are typically still carried as braces and wheelchairs are expensive, not easily available, or unusable due to the rough terrain. Low cost aids to improve activities of daily living (ADLs) may result in an improved QOL for both children and parents.

Incontinence appears to be one of the most stressful aspects of SB, even more than impaired motor function. Bladder problems may act as a focus of strain on family relationships, but CIC itself was well tolerated.

Our data supports the evidence that incontinence has a negative...
impact on marriage, while CIC appeared to positively impact social life.

The social acceptance of people with visible disabilities remains an issue in Kenya. One well-educated mother said: ‘Many family members, even the grandparents, have not seen the baby because they are afraid of a curse’. The curse idea, with a resulting lack of support received from the extended family, was also prominent in a Nigerian study of SB and hydrocephalus – the early treatment of the baby’s deformities was, in fact, sought in order to allow the baby to look ‘normal’ before being seen by the community.9

This study documents the pervasive social, financial, emotional and spiritual impact that SB has on the QOL of the family in a developing country. Family resources, such as hope and instrumental support, are predictors of QOL in children with SB.5 In our study, mothers who received help from their community or church found it very beneficial. Support groups for parents of children with disabilities are relatively new in Kenya but are growing rapidly, mainly due to the introduction of public education. Indeed, education is essential for the prevention of social isolation and for providing support. Medical providers, faith and other communities and empowered parents can all be agents for the education of the public and advocates for change.

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