

Experiences of children living with spina bifida and their parents in Uganda - 'I like being at home, they are used to me'

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AIM

To share experiences of living and belonging of children with spina bifida and their parents in Uganda. The findings reported here are part of an ongoing larger study on inclusion and quality of life of children with spina bifida in Uganda.

METHODS

Semi structured interviews were held with 97 children with spina bifida between 4 and 14 years of age, and 132 parents in 5 locations in Uganda. Home and/or school observations were conducted for 36 of the children. NVivo was used for data analysis.



SPINA BIFIDA

Spina bifida ('open back') is a congenital disability, whereby the spinal cord and vertebrae do not form completely and the neural tube fails to develop normally. This

usually causes some degree of paralysis, which affects mobility as well as bowel and bladder control. 66% of children with spina bifida in low income countries also develop hydrocephalus ('water in the brain'). Hydrocephalus is an abnormal expansion of ventricles caused by an imbalance between production and absorption of cerebrospinal fluid.

RESULTS



Mean age of the children
6.1 years, median 6.0

56.8% male
43.2% female

58.3% spina bifida,
41.7% both spina bifida
and hydrocephalus

Average household size
6.5 persons

Primary caregivers of the
children: 77.3% mother,
10.6% father, 7.6%
grandmother, 4.5% others

Marital status caregivers:
75.0% married, 8.3% single,
8.3% separated, 6.8%
widowed



Junior (5 years) sits at the door of his house watching the neighbours' children play. He lives in a one roomed house in Kampala, Uganda's capital city together with his parents and siblings: 'I am looking at my friends. I like to play with them but when my toes bleed I am not allowed to crawl outside'.

Grace (8 years) lives with her grandmother in a mud house on a hill top in eastern Uganda. Her mother works in town. She does not go to school and rarely sees other people. Her grandmother cannot carry her down the hill. Even if she had a wheelchair there is no road or path to ride it on.

Theme	Personal perspectives children	Personal perspectives parents / caregivers
Family	Close relationships with (grand) mother and siblings. Participation in household tasks.	Special relationship due to high dependence. Stigma and negative attitudes of inlaws.
Community	Bullying and beating by other children. Exclusion from games, community events. Better relationships with neighbouring children.	Rejection by communities. Social isolation of child due to limited mobility and stigma. Over time perspectives change.
Health	Limited possibilities to practice catheterization outside home.	Incontinence interferes with daily life. Transport and treatment costs challenging.
School	Verbal abuse by peers. Limited understanding from teachers. No participation in sports.	Physical accessibility, school fees and acceptance are challenging. Teachers change perspectives after close follow up by parent.
Future	Would like to help other children with disabilities, e.g. become doctors, lawyers, teachers.	Worry about life long dependence of child.

CONCLUSIONS

Children with spina bifida have a strong sense of belonging in their families and smaller community network. They are more ambivalent about their position in school and their wider community. They have expectations about their future which are often related to helping other children in similar situations. Parents describe more challenges with the living experiences and foreseen future. Community and school interventions to reduce stigma and promote inclusion are recommended alongside support for parents and caregivers.