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.

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, 8.8% widowed

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 foresee a future. Community and school interventions to reduce stigma and promote inclusion are recommended alongside support for parents and caregivers.