

**Stigmatization, discrimination, and
exclusion of children with spina
bifida and hydrocephalus in
northern Uganda**

**Femke Bannink - Mbazzi, Joyce Laker,
Richard Idro, Geert van Hove**

Introduction

The war and disability in northern Uganda:

- War related injuries (landmines, gunshots)
- Poor feeding (malnutrition, lack of folic acid)
- Lack of antenatal, delivery and postnatal care
- High risk of disease (e.g. meningitis)



Spina Bifida



Hydrocephalus



Research question

Is there a difference between the daily functioning and inclusion of children with spina bifida and hydrocephalus living in the war affected northern region compared to similar children in the other non war affected regions of Uganda?

Study population

- 57 children with spina bifida and hydrocephalus between 4 and 14 years of age from Acholi and Lango sub-regions (north)
- 165 children from central, east, and western regions
- Recruitment through rehabilitation centers and tracing in communities



Methods

- Semi structured interviews
- Observations
- Vineland Adaptive Behavior Scales
- Strengths and Difficulties Questionnaire

- SPSS was used for data analysis, e.g. cross tabulations, and t-tests. NVIVO was used to analyse qualitative data from interviews.

Results

1. Demographics
2. Attitudes
3. Health seeking behaviour
4. Daily functioning
5. Social relationships
6. Education

Results (1) Demographics

Child's age in years	Region / location				
	Central	East	West	North	Total
4 – 5	40 (52.7%)	12 (31.6%)	20 (39.2%)	26 (45.6%)	98 (44.1%)
6 – 8	26 (34.1%)	18 (47.4%)	20 (39.2%)	26 (45.7%)	90 (40.5%)
9 – 11	8 (10.5%)	6 (15.8%)	9 (17.6%)	5 (0.9%)	28 (12.6%)
12 – 14	2 (2.6%)	2 (5.3%)	2 (4.0%)	0 (0%)	6 (2.7%)
Total	76 (34.2%)	38 (17.1%)	51 (23.0%)	57 (25.7%)	222 (100%)
Mean age	6.0	6.9	6.6	5.8*	6.2

* F=2.54 (p<0.05)

Monthly household income

Monthly income in Ugandan shillings	Central	East	North	West
<100,000	5 (7.6%)	3 (4.5%)	40 (60.6%)	18 (27.2%)
100,000 - 200,000	14 (32.6%)	14 (32.6%)	8 (18.6%)	7 (16.3%)
200,000 - 300,000	14 (35.9%)	11 (28.2%)	6 (15.4%)	8 (20.5%)
>300,000	36 (60.0%)	8 (13.3%)	2 (3.3%)	14 (23.3%)

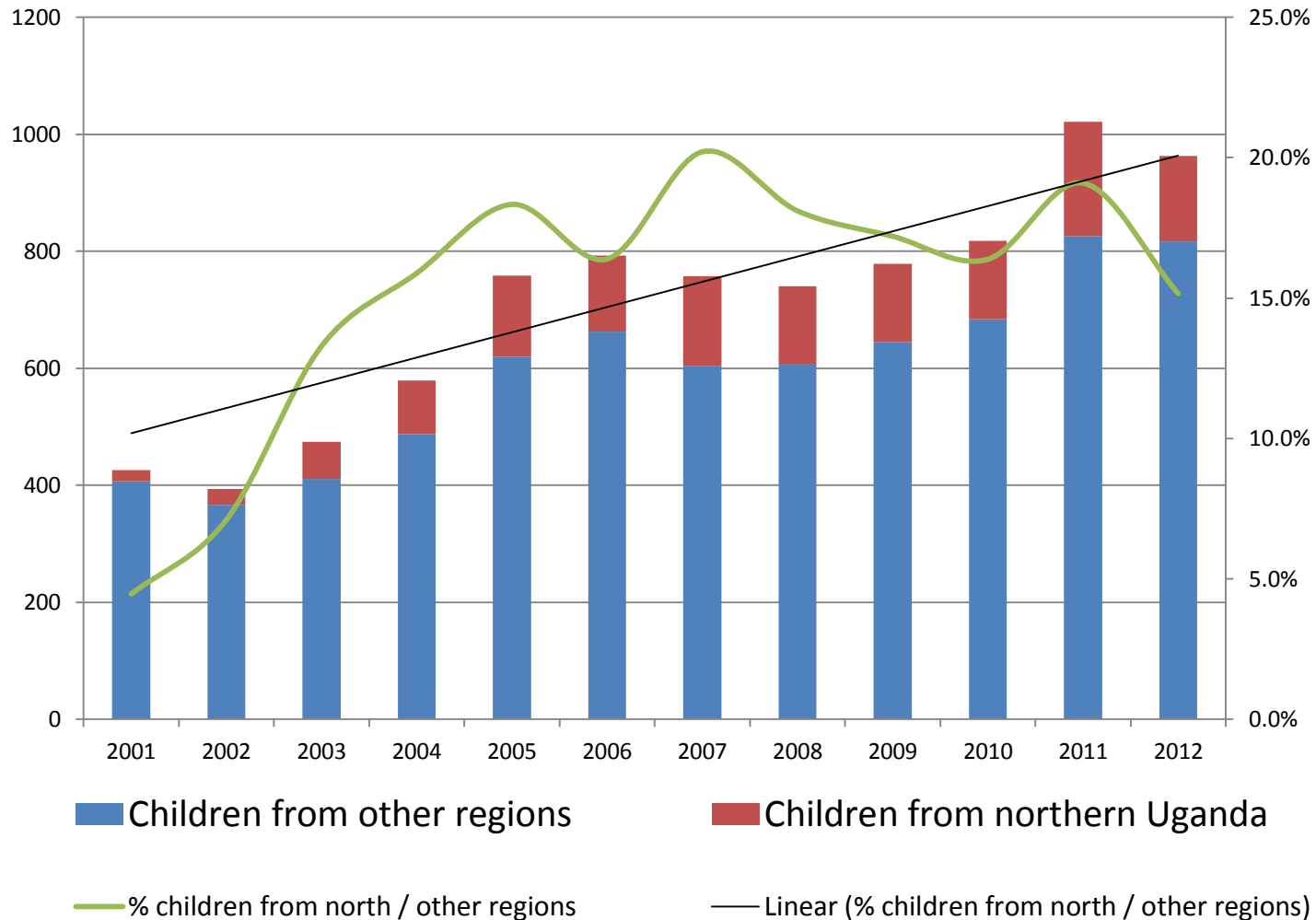
Result (2) Attitudes (qualitative data)

- Parents report stigmatization, discrimination and exclusion of their child in all regions
- Community members believe the child is bewitched and may be infectious only in northern Uganda
- Mothers are abandoned by their husbands and in laws in all regions, but more in the north

Results (3) Health seeking behavior

- Before and during the war children with SBH were 'accidentally untied' from the mother's back while crossing a river leading to drowning
- Rehabilitation center receives less reports of 'drowning' and more requests for rehabilitation for children with SBH since 2006

Number of children with Spina Bifida and Hydrocephalus admitted and treated at CURE hospital from 2001-2012



Results (4) Daily Functioning

Children in the northern region have lower scores on motor abilities and daily functioning compared to children from other regions

Variable	Sum of Squares	df	Mean Square	F	P-value
Child is able to sit	0.668	3	0.223	4.935	0.002*
Child is able to talk	2.311	3	0.770	10.015	<0.001*
Child is able to walk	1.824	3	0.608	2.504	0.06
Vineland Daily Functioning Score	504.285	3	168.095	3.487	0.018*

Result (5) Social relationships

Children from the northern region have lower scores on social skills, social and peer relationships subscales compared to children from other regions.

Subscale scored	Sum of Squares	df	Mean Square	F	P-value
Vineland social subscale	129.926	3	43.309	4.562	0.005*
SDQ peer subscale	67.542	3	22.514	6.934	<0.001*
SDQ social subscale	238.000	3	79.333	4.700	0.004*

Result (6) Education

In Uganda 83% of all children in primary school age attends school. In northern Uganda 78%. Children with SBH are less likely to be in school. Of those in school, the majority is bullied.

Children with SBH	Central	East	North	West	Total
Not schooling	26 (36.1%)	19 (50%)	33 (66%)	17 (34%)	95 (45.2%)
Nursery school	30 (41.7%)	12 (31.6%)	6 (12%)	24 (48%)	72 (34.2%)
Primary school	12 (16.7%)	5 (13.2%)	7 (14%)	9 (18%)	33 (15.7%)
Secondary school	4 (5.6%)	2 (5.3%)	4 (8%)	0 (0%)	10 (4.8%)
Total	72	38	50	50	210

Result (6) Age Appropriate Education

While children with SBH in the north are not significantly different from children with SBH in other areas in schooling, they are less likely to be in an age appropriate class compared to children in other areas of Uganda.

Variable	Sum of Squares	df	Mean Square	F	P-value
Child in school	1.164	3	0.546	2.397	0.072
In age appropriate class	37.115	3	12.372	2.670	0.048*



Conclusion

- Changing cultural practices and availability of health care services in the northern region towards the end of the war may have reduced the early deaths of children with SBH
- Community attitudes towards children with SBH remain negative in northern Uganda
- Functioning and inclusion of children with SBH in northern Uganda remains lower than in other parts of the country

Recommendations

- Positive change in health seeking behavior has to be supported and expanded
- Increase community sensitization on the cause, prevention and treatment of congenital disabilities to improve inclusion
- Need to invest in rehabilitation services, and inclusive education in the northern region to improve functioning and inclusion
- Further studies to assess the impact of war on children with disabilities and their families

Thank you
Contact: femke.bannink@ugent.be

