Mobility, incontinence, and social functioning of children with spina bifida in Uganda

Femke Bannink Mbazzi & Geert van Hove
Republic of Uganda

- Population: 32 million
- Language: English and local languages
- Capital city: Kampala
- Life expectancy: 52.3 years
- Fertility rate: 7.2
- Growth rate: 3.6%
- 17 Bantu and Nilotic tribes
- War in northern region from 1984 - 2006
Spina Bifida
Spina bifida in Uganda

- 1-2 in 1,000 live births; estimated 1,400 / year (Warf, 2011). Approximately 10% of these receive neurosurgical care. The remaining most likely dies.

- Prevention: poor feeding, malnutrition, lack of folic acid intake, poor antenatal care (Miles, 2006)

- Barriers to treatment: lack of knowledge (Mertens and Bannink, 2012), negative attitudes and beliefs (Bannink, Idro, van Hove 2013), poverty (Miles, 2006).
Study population

- Part of a larger quality of life study, looking at daily, social, cognitive, and family functioning
- 132 parents of children with spina bifida aged 4 to 14 years
- Recruitment through rehabilitation centers and tracing in communities
- In 5 locations in Uganda
Methods

• Semi structured interviews
• Vineland Adaptive Behavior Scales – daily and social functioning subscales
• Strengths and Difficulties Questionnaire – pro-social behaviour, and relationships with peers
• SPSS was used for data analysis.
• NVIVO was used to analyze qualitative data from interviews.
<table>
<thead>
<tr>
<th>RESULTS</th>
<th>Demographics</th>
</tr>
</thead>
</table>
| Sex child       | 56.8% (75) male  
43.2% (57) female                                           |
| Age child       | 4 – 14 years, median 6.1 years                                               |
| Condition child | 58.3% (77) spina bifida  
41.7% (55) spina bifida with hydrocephalus  |
| Household size  | \( \bar{x} = 6.6 \) persons in the household (2 – 13)                       |
| Relationship caregiver | Mother 77.3% (102)  
Grandparent 7.6% (10)  
Father 10.6% (14)  
Other 4.5% (6) |
| Marital status caregiver | Single 8.5% (11)  
Separated 8.5% (11)  
Married 76.2% (99)  
Widowed 6.9% (9) |
| Location / region | Central 47.7% (63)  
East 19.7% (26)  
West 21.2% (28)  
North 11.4% (15) |
## Results - Social functioning

<table>
<thead>
<tr>
<th>Variable</th>
<th>Relationship with peers</th>
<th>Pro-social behaviour</th>
<th>Social communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily functioning skills</td>
<td>2.18*</td>
<td>25.91***</td>
<td>33.04***</td>
</tr>
<tr>
<td>Lack of assistive devices</td>
<td>0.91</td>
<td>4.18*</td>
<td>2.41*</td>
</tr>
<tr>
<td>Incontinence</td>
<td>0.08</td>
<td>0.52</td>
<td>3.00</td>
</tr>
<tr>
<td>Practices CIC</td>
<td>2.11</td>
<td>13.38***</td>
<td>10.45***</td>
</tr>
<tr>
<td>Schooling</td>
<td>0.54</td>
<td>2.14</td>
<td>2.39</td>
</tr>
<tr>
<td>Parent support group</td>
<td>0.09</td>
<td>8.23**</td>
<td>5.63*</td>
</tr>
<tr>
<td>Region</td>
<td>6.93***</td>
<td>4.70**</td>
<td>4.56**</td>
</tr>
</tbody>
</table>

F-scores * p<.05; ** p<.01; *** p<.001
Daily functioning

Ruth was born with spina bifida and hydrocephalus. She is 8 years old, and lives with her mother in a slum in Kampala, Uganda's capital city. She attends a local school near home.
Mobility and assistive devices

63.6% (84) of the children interviewed need assistive devices for mobility:
• 29.8% (25) use a wheelchair (7.6% of them on their own)
• 21.4% (18) uses crutches
• 6.0% (5) use walking frames
• 42.9% (36) crawled due to lack of access or use of a device. Almost all these children have pressure sores, mostly on their feet
Incontinence and CIC

- 89.4% (118) is incontinent, and practices bowel wash out (70.5%) and clean intermittent catheterization (75.8%). 15.9% practices CIC, and 4.9% practices bowel management on their own.

- Practicing in school and public places is difficult due to lack of facilities and adults to. In school 15.2% can practice.
Schooling

- 55% of children with SB in school vs 83% nationally
- Approximately 1 year behind their age mates
- Reasons for not schooling: inaccessibility, financial problems, incontinence, and bullying

<table>
<thead>
<tr>
<th>Children with spina bifida</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not schooling</td>
<td>58 (45.0%)</td>
</tr>
<tr>
<td>Nursery school</td>
<td>46 (35.7%)</td>
</tr>
<tr>
<td>Primary school</td>
<td>21 (16.3%)</td>
</tr>
<tr>
<td>Secondary school</td>
<td>4 (3.0%)</td>
</tr>
</tbody>
</table>
Parent Support Groups

- 38.9% (51) parents are members of parent support groups (self help groups)
- 48.1% (63) have support from another adult in the care for their child
Geographical differences

<table>
<thead>
<tr>
<th>Subscale scored</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vineland social subscale</td>
<td>129.926</td>
<td>3</td>
<td>43.309</td>
<td>4.562</td>
<td>0.005</td>
</tr>
<tr>
<td>SDQ peer subscale</td>
<td>67.542</td>
<td>3</td>
<td>22.514</td>
<td>6.934</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>SDQ pro-social subscale</td>
<td>238.000</td>
<td>3</td>
<td>79.333</td>
<td>4.700</td>
<td>0.004</td>
</tr>
</tbody>
</table>

Children with spina bifida from the war affected northern region have lower social functioning scores compared to children from other regions.
## Results – Predictors Social functioning

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Relationship with peers β</th>
<th>Pro-social behaviour β</th>
<th>Social communication β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily functioning skills</td>
<td>0.52**</td>
<td>0.57**</td>
<td>0.65***</td>
</tr>
<tr>
<td>Lack of assistive devices</td>
<td>-0.07</td>
<td>-0.03</td>
<td>0.04</td>
</tr>
<tr>
<td>Incontinence</td>
<td>0.10</td>
<td>0.07</td>
<td>0.14</td>
</tr>
<tr>
<td>Practices CIC</td>
<td>-0.07</td>
<td>0.24</td>
<td>0.15</td>
</tr>
<tr>
<td>Schooling</td>
<td>0.41*</td>
<td>0.16</td>
<td>0.21*</td>
</tr>
<tr>
<td>Parent support group</td>
<td>-0.11</td>
<td>0.20</td>
<td>0.14</td>
</tr>
<tr>
<td>Region</td>
<td>0.32*</td>
<td>-0.11</td>
<td>0.12</td>
</tr>
</tbody>
</table>

Multiple regression analysis * p<.05; ** p<.01; *** p<.001
Recommendations

• To improve social participation of children
  – improve daily functioning skills through early intervention and community based rehabilitation
  – use of catheterization at home and public places
  – support inclusion in schools
  – provision of relevant assistive devices
  – promoting participation in parent support groups
  – specific interventions in the war affected north

• Longitudinal studies to assess predictors and evaluate interventions to promote social functioning and inclusion over time
Thank you

femke.bannink@ugent.be