

## **Family relationships, support and care: perspectives of children with spina bifida in central Uganda**

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In Uganda, public health and education services are poorly equipped to respond to needs of children with spina bifida. Such children are highly dependent on their families for care and support. In this study, we explore the children's and their siblings' perceptions of family relationships, support, restrictions and care to inform policy and practice for the children and their families. Semi-structured interviews were held with 30 children with spina bifida, and 30 of their siblings in central Uganda. Using the Family Relations Test, we created a set of local dolls and culturally appropriate messages to evaluate the children's feelings about their family members and themselves. Our findings confirm a highly interdependent and supportive family care model in which mothers play a key role in the children's lives and care; fathers are relatively absent for both children with spina bifida and their siblings; siblings, and other household members play an important role in the care and social inclusion of children with spina bifida; and children with spina bifida have more negative self-perceptions compared to their siblings. The internal family networks of children with spina bifida in Uganda are wide and varied, and characterized by higher support from mothers and elder siblings and househelps. We argue for an extended family centered approach in health care and social services, in which children with spina bifida, their parents (including their fathers), siblings, house-helps and other family members are included. We believe family led advocacy for inclusive care and support services on community and national level is key to enable a shift in the current service model and thinking about persons with disabilities in the country.

**Keywords:** children; spina bifida; family relationships; extended families; persons with disabilities; care; Uganda

### **Introduction**

Spina bifida is a neural tube defect, a congenital disability, whereby the spinal cord and vertebrae do not form completely and the neural tube fails to develop normally. In Uganda incidence data is not available. In Uganda, Warf et al (2011) estimated a birth incidence of 1 in 1,000, translating

into 1,400 children born with spina bifida in the country annually (Warf et al., 2011). Most children with spina bifida have some degree of paralysis, which affects mobility as well as bowel and bladder control (Northrup and Volcik, 2000). Hydrocephalus is another common complication. Sixty-six per cent of children with spina bifida, in low-income countries, develop hydrocephalus (Warf et al., 2009). As a result, children with spina bifida and their families must manage medical and rehabilitative care including catheterization, bowel management programs, assistive devices, and skin checks to avoid pressure sores (Lindsay, 2014). Aside from these physical needs, research has shown that children with spina bifida are prone to neurocognitive deficits in executive function (involving organization, impulse control, working memory, and flexible thinking), attention and learning difficulties (Dennis and Barnes, 2010), and they often face social skills and inclusion challenges (van't Veer et al., 2008). Children often rely on their family members for social interaction (Holmbeck and Devine, 2010).

Research on functioning and psychosocial adjustment of families of children with spina bifida in high income countries supports a resilience–disruption view, whereby the presence of a child with spina bifida disrupts normative family functioning at first, but after a period of time, families adapt and exhibit considerable resilience (Holmbeck et al., 1997; Vermaes et al., 2007). Nevertheless, spina bifida has negative effects on parents' psychological adjustment and functioning (Vermaes et al., 2008; Holmbeck and Devine, 2010). Stress levels of parents of children with spina bifida are higher than parents of typically developing children (Kanaheeswari et al., 2011, Holmbeck et al., 1997). Caregivers of children with disabilities often feel that they do not have sufficient time to cope with household tasks, and feel isolated (Hartley et al., 2004, Gona et al., 2011). A study on adjustment and sibling relations in families with a child with spina bifida in the US (Bellin and Rice, 2009), found children with spina bifida were more likely to feel satisfied with family functioning when they experienced warmth and limited conflict in their relationship with their sibling(s). No negative impact of spina bifida on marital functioning has been found in previous studies (Holmbeck et al, 1997). Sometimes having a child with spina bifida has been found to strengthen the marriage (Cappelli et al., 1994; Kazak and Clark, 1986).

In Uganda and other East and Southern African countries, formal public rehabilitative and social services are limited for children with spina bifida and their families (Mertens and Bannink, 2012). The children's families are often their main source of care and protection (Miles, 2006). Families in Uganda do not receive government support, and public health and education services are poorly equipped to respond to the needs of the children (Bannink et al., 2016c). A few civil society organizations aim to provide basic surgery and rehabilitation services for children with spina bifida and involve parents as the key stakeholders at the community level (Mertens and Bannink, 2012). Across the region, families of children with neuro-disabilities, including spina bifida, struggle with the financial implications and social barriers towards care and support for

their child, including Uganda (Bannink et al., 2015), Kenya (van't Veer et al., 2008), Malawi (Paget et al., 2015) and South Africa (Coomer, 2013).

Little is known about children with spina bifida and their families in Uganda. In previous studies conducted by the authors, parents of children with spina bifida have been discouraged from taking care of their child by relatives, neighbours, and health workers (Bannink et al., 2015). Although attitudes are changing over time, inaccessibility of services and negative perceptions held by the community at large, continue to affect the care and inclusion of the children (Bannink et al., 2015). High parental stress was found in mothers and grandmothers looking after children with disabilities in Uganda and Kenya (Hartley et al., 2004, Gona et al., 2011). In Uganda, parental stress is higher in parents of children with spina bifida with limited mobility, those who have no support of another adult in the provision of care, and who require daily continence management exercises (Bannink et al., 2016c). Social inclusion of children with spina bifida tends to be limited to the household level and is affected by poverty and stigmatization; the children have a sense of belonging at home in which participation in daily household activities plays an important role, but participation in social life outside the home is often dependent upon siblings who accompany the child with spina bifida to play with other children in their communities, or help them to get to school (Bannink et al., 2016b)

To further explore family relationships, support, and care in families of children with spina bifida in Uganda, we interviewed children with spina bifida and their siblings, using the Family Relations Test (FRT). The FRT is a psychological test which evaluates a child's perspective about their family relationships and themselves, and measures outgoing and incoming negative and positive feelings for each family member, as well as feelings of 'dependence' or need for support from others (Bene and Anthony, 1985). Through the use of the FRT in interviews with children with spina bifida and their siblings in Uganda, we explore both qualitatively and quantitatively how the children perceive their relationships towards their family members. We included both children with spina bifida and their siblings in the study to explore the family relationships of, and interdependency between, both groups of children. The siblings functioned both as a control group for understanding the experience of the children with spina bifida and as an independent source of valuable insights about their own experience, as recognised enablers of social inclusion within the family (Bannink et al, 2016b). The study aims to provide recommendations for civil society and government programs on support to families with children with spina bifida.

## Method

This section describes the research sample, study tool used, methods of data collection and analysis, and ethical procedures followed in the study.

## Sample

Participants in this study were 30 children with spina bifida and 30 of their siblings aged 4 to 14 years from central Uganda. The sample was taken from a larger social inclusion study of 139 children with spina bifida in Uganda. The following inclusion criteria were used to select the participants: they had to i) reside in the central region (51 children out of the 139 in the larger sample); ii) have the cognitive ability to understand, participate, and complete the FRT (38 out of the 51 children), based on earlier cognitive test findings (Bannink et al., 2016a); and iii) have a sibling who was willing and available to participate (30 out of the 38 children). Elder and younger siblings, closest in age to the child with spina bifida and living in the same household to them, were purposefully selected during home visits. The purpose of selecting the sibling closest in age was to enable comparisons between perceived family relationships without a large age bias (e.g. perceptions of relationships between teenagers and parents may differ from those of younger children, and older children may be more independent and require less parental support compared to younger children).

In total, 17 boys and 13 girls with spina bifida participated in the study, and 14 brothers (7 elder, 7 younger), and 16 sisters (9 elder and 7 younger) participated in the study. The average age of the children with spina bifida was 9.20 (SD=2.37) years, and the average age of the siblings was 9.13 (SD=1.98) years. The average household size was 7 persons (ranging from 3 to 11). The majority (22/30) of the children's parents were married and living together. Data was collected during routine visits to the children's homes and to a clinic providing neuro-surgical follow up and rehabilitative care to children with spina bifida in Kampala. The rehabilitative care is offered by a community based rehabilitation (CBR) worker, who provided physiotherapy, occupational therapy, training in catheterization, and parental support at rehabilitation centers and home visits. All the children with spina bifida who participated in the study had received neurosurgery and physiotherapy, and were practising continence management. Both the children with spina bifida and their siblings were in school. The average household income of their families was US\$87 per month.

## **Data collection**

Semi-structured interviews were held with the 30 children with spina bifida, and the 30 siblings about family relationships, supports and restrictions, care and inclusion, using the Family Relations Test.

### *Study tool*

The Family Relations Test (FRT) was developed by Eva Bene and James Anthony in 1957, and revised in 1978 and 1985 (Bene and Anthony, 1985). Translations have been made into various languages, and adaptations made to allow for more quantitative analysis and comparison of the findings (Celestin-Westreich et al., 1999). The FRT evaluates a child's perspective about their family relationships and themselves, and measures their positive and negative feelings towards each family member, as well as their need for support and care or independence from each family member (Bene and Anthony, 1985). The test is designed for use with children aged 3 to 7 years and 8 to 15 years respectively. Two versions of the test are available for these age groups (Bene and Anthony, 1985).

The FRT employs cardboard figures to represent different members of the family, including the child undertaking the test. There are 20 cardboard figures, from which the child can select to represent each family member. The cardboard figures have folded mailboxes into which children can place up to 40 cards, each bearing a single emotional statement or attitude they may feel towards their family members. The child reads (or is read) the statement on each card, and is asked to assign the card to one of the figures. There are 16 cards bearing positive statements, including 8 'inward positive' cards that show who supports, cares and plays with the child, and 8 'outward positive' cards that show who the child goes to for support, care, and play. There are also 16 cards bearing negative statements, including 8 'inward negative' cards which describe who chastises and disciplines the child, and 8 'outward negative' cards which describe who the child does not like, is competitive with, and fights with. Finally, there are 8 'dependency' cards which measure the child's need for support and care or independence from others. In this paper we refer to these as 'independence' cards. If the statement is not applicable to any of the represented family members, the card is given to the figure "Nobody". After all of the cards have been distributed, scores are tallied on a form.

The FRT test as published by Celestin-Westreich et al (1999) was analyzed, adapted, translated, and administered by the authors - psychologists, educational scientists, and social workers with over 25 years combined working experience with children with spina bifida in Uganda. In this version, a child can give the card to only a single family member, which makes it possible to quantify the number and percentage of cards each family member received and compare results. It has been used in therapy with traumatized children from multi-cultural settings in Belgium and

The Netherlands. Advice on adapting this version of the FRT for use in Uganda was requested and received from Prof. Dr. S. Celestin-Westreich.

Subsequently, the text on the cards was translated into Luganda, the language spoken in the central region. The text on the card 'who would you like to give a kiss' (a positive outgoing message card) was changed into 'who would you like to give a hug', as kissing is not a culturally common form of expressing affection or greetings in Uganda. While in the original version, the cards are entered into mailboxes on the cardboard figures used to represent family members, the cards in the Ugandan setting were placed next to a doll that represented the relevant family member, since most children are not familiar with a postbox system. The Caucasian-looking cardboard figures were replaced by locally made dolls, dressed in African clothes. In total 20 dolls were made, representing persons of both sexes and different ages (including grandparents and babies).



**Image 1. Photo of the dolls**

Two versions of the test – one for younger children and one for older children - were initially piloted with 12 school going children (6 children with spina bifida and 6 siblings) age 4 to 13. All children easily associated the dolls with their family members and enjoyed participating. The cards were read to all children, as the majority could not read and complete the test on their own. The statements on the cards, in the version for younger children, were easily understood. However, the statements on the cards in the version for older children often led to confusion and the higher number of cards often resulted in disengagement of the child at the end of the test. When the older children were given the version for the younger ones, these challenges did not occur. Administration of the version for older children took approximately 52 minutes, whilst the version for younger children was completed within an average of 28 minutes. We decided to use only the version for younger children for all the children and siblings who participated in this study.

### *Data analysis*

Interviews were transcribed and thematic analysis was conducted using NVIVO16. The interview data included examples and stories told by the child during administration of the FRT. For example, a child would assign an FRT card 'who do you like to play with' to a sibling, and narrate a story about playing a game with his brother. FRT results were recorded and entered into a database. For each child, a summary was made of the total number of positive and negative incoming and outgoing feelings, and 'independency' cards, as per test categories and instructions. Positive and negative incoming and outgoing feeling scores were totaled into one positive and one negative score. 'Independency' scores were totaled for each family member, summarizing the child with spina bifida and their sibling's feelings towards them regarding their need for support and care or independence. Summaries and averages were grouped for the children with spina bifida and older and younger siblings. Averages and standard deviations of cards given per family member were calculated based on family size and selected family figures. A two-tailed T-test was utilized to test if there would be a significant difference between the assignment of cards by children with spina bifida and their siblings to their family members.

### *Ethics*

Ethical approval and research clearance were obtained from Ghent University, Belgium, the Uganda Virus Research Institute, and the Uganda National Council for Science and Technology. Informed consent was obtained from all parents, and assent from children and siblings eight (8) years or older where possible, in accordance with ethics guidelines of Ghent University and the Ugandan Research Council. The use of dolls as a method to help children talk, describe, and work through difficult situations was discussed with the community based rehabilitation (CBR) worker involved in the follow up program of the children with spina bifida who participated in the study. The CBR worker fulfilled the role of physio, occupational therapist and social worker for the children, as no resources are available to employ a multidisciplinary team in our setting. Individual results of the FRT and interviews with the children were also shared with the CBR worker.

## **Results**

### **Family composition**

Children were asked to describe their families. Most of them named their family members and explained where they live.

'My mum, and my brother, and my sister, and my baby sister, and my father, and my auntie.' Boy with spina bifida (6)

‘I have two brothers and three sisters. And my mum and my dad. We live in Nsambya’  
 Girl with spina bifida (11)

**Table 1. Average number of cards and two tailed T-test results for children with spina bifida and their siblings’ family perceptions (N= 30 children with spina bifida and N=30 siblings)**

Person receiving card	Type of card	Average number of cards given (SD)		Levene's Test	t-test
		by CwSB (n=30)	by Siblings (n=30)	F-value	T
Self	Positive	0.52 (1.52)	0.07 (0.25)	7.989**	1.535
	Negative	0.59 (0.89)	0.13 (0.25)	21.080***	2.467**
	Independence**	1.14 (1.36)	2.63 (0.34)	0.006	-3.755***
Father	Positive	1.71 (1.61)	1.20 (1.38)	0.611	1.200
	Negative	1.19 (1.50)	1.33 (1.58)	0.013	-0.318
	Independence	0.65 (0.79)	0.59 (0.94)	0.296	-0.044
Mother	Positive	4.38 (2.59)	4.40 (2.65)	0.081	0.000
	Negative	1.52 (1.75)	0.67 (0.91)	13.534***	2.300*
	Independence	3.11 (1.78)	3.86 (1.75)	0.404	-1.599
Grandmother	Positive	0.24 (1.28)	0.67 (1.72)	4.804*	-1.096
	Negative	0.17 (0.91)	0.07 (0.36)	1.332	0.557
	Independence	1.33 (1.25)	1.50 (0.87)	0.653	-0.176
Older sibling	Positive	3.76 (3.68)	7.90 (2.72)	4.017*	-4.538***
	Negative	5.00 (4.41)	8.07 (3.14)	5.670*	-3.116**
	Independence	0.93 (1.96)	1.03 (1.05)	7.417**	-0.326
Younger sibling	Positive	3.00 (3.35)	0.53 (1.56)	19.311***	3.455***
	Negative	2.10 (4.04)	0.53 (1.87)	7.261***	1.833
	Independence	0.72 (1.39)	0.10 (0.40)	17.582***	2.266*
Sibling (total)	Positive	6.76 (3.29)	8.43 (2.67)	1.152	-1.994*
	Negative	7.10 (4.24)	8.60 (3.37)	1.451	-1.599
	Independence	1.66 (2.06)	1.13 (1.09)	12.109***	1.086
Other	Positive	0.76 (1.72)			
	Negative	0.66 (1.49)			
	Independence	0.34 (0.88)			
Mr Nobody	Positive	2.10 (2.31)	1.37 (1.08)	2.753	1.495
	Negative	5.10 (3.94)	5.30 (2.61)	6.573**	0.000
	Independence	0.59 (0.89)	0.27 (0.63)	19.127***	3.837***

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

\*\*\*\* Independence cards measure the need for support to carry out daily activities; children with lower scores are more independent.

When asked to select a doll for each family member, twenty eight (28) children selected a mother figure. Two (2) children were looked after by a grandmother and had no mother present. Another two (2) children added a grandmother as well as a mother in their family composition. Twenty two (22) children selected a father figure. All children selected at least one sibling; the majority selected 4 or more siblings.

FRT results were entered for each individual family member. Table 1 shows a summary of the findings with the average numbers of FRT cards given to each family member for parents, siblings, and other family members. Sibling results were grouped into younger, older, and total siblings. Findings for other relatives and house helps were summarized in one group.

The family set-up depicted by the children often differed from the family set-up given by the parent. In total, 6 (six) children left out fathers who worked upcountry, and twelve (12) children left out siblings who were in boarding school, and were only around during weekends and/or holidays. Twenty six (26) children with spina bifida included 'other' relatives and househelps in their family selection; siblings did not include any.

### **Family relationships**

Children with spina bifida were asked to tell the interviewer about their family members. The children gave examples of situations that had occurred with family members, and described different roles and relationships in their narratives. Most of these were related to care, family disputes or restrictions applied to children's time to play outside or expectations towards school work.

'My parents look after us. My dad pays school fees. My mum cooks and she takes me to the clinic. I play with my brothers and my sister'. Sister (7) to a girl with spina bifida (10)

'My brother always gets into trouble. He never does his homework. My dad gets very angry and beats him when he comes home. He does not beat me, my mum told him it is not good for my head' Girl with spina bifida and hydrocephalus (12) about her elder brother (14)

'Jjajja [grandmother] lives with us, she is very old, she likes to tell stories' Sibling (7) of a girl with spina bifida (5)

'On Sundays we all go to church together.' Girl with spina bifida (5) about her family

The positive cards were generally distributed amongst three (3) or four (4) family members. The inward positive cards were mostly given to mothers, and elder siblings. Some were given to other family members by children with spina bifida. The outward positive cards were mostly given to mothers, younger siblings for children with spina bifida, and older siblings for the siblings interviewed. No significant differences in positive perceptions about parents were found between children with spina bifida and siblings. Children with spina bifida gave less positive ( $t=-4.538$ ,  $p<0.001$ ) cards to their older siblings compared to their siblings, but they gave more positive cards to their younger siblings than their siblings ( $t=3.455$ ,  $p<0.001$ ). In discussions about their positive feelings, children gave more details about what their family would do to make them feel loved, or who they enjoyed to play with. Most spoke about their mothers and siblings; only a few spoke about their fathers.

‘My mum carries me and she tells me stories’. Girl with spina bifida (6)

‘My sister pushes me to school’ Girl (8) with spina bifida using a wheelchair

‘I like to play with my sister, she likes to play meso [a board game] with me’. Boy with spina bifida (10) about his younger sister (8)

‘I help my little brother with his homework’ Boy with spina bifida (11)

‘My little brother comes and sits on my lap and gives me hugs’. Girl with spina bifida (6)

‘I like to play football. My brother watches. I push his wheelchair to the field’. Older brother (14) about his younger brother with spina bifida (12)

‘My brother helps me when I am scared. He takes me with him and protects me’. Elder sister (11) of a girl with spina bifida (6) about her brother (15)

‘My aunt [househelp] gives me food’ Boy with spina bifida (4)

Negative inward and outward cards were mostly given to elder siblings. Children with spina bifida gave significantly less negative ( $t=-3.116$ ,  $p<0.001$ ) cards to their elder siblings compared to their siblings. Children with spina bifida perceived more negative interactions with their mothers than their siblings ( $t=2.30$   $p<.05$ ), e.g. ‘this person does not like me’. Similar perceptions were found by the children living with their grandparents. In discussions with the children, they would describe what they did not like in the relationship to the family member they gave their card to:

‘My mum does not let me play with the other children’. Boy with spina bifida (6)

‘Mum shouts at me’ Girl with spina bifida (4)

Some siblings expressed negative feelings towards their sibling with spina bifida:

‘He needs to be helped all the time. My mum has no time to help me with my homework because she is always busy with him’ Elder sibling (14) of a boy with spina bifida (9)

No differences were seen between children with spina bifida and siblings in perceived family relations with fathers. When asked about their fathers, most children described their profession. In a few families, fathers were involved in the care of their child with spina bifida, and in two families the father took the child to the rehabilitation center for follow up and review. The most common positive outward feeling card that children gave to the father figure was a card with the message ‘who repairs your toys when they are broken?’.

### **Perception of self, and of support, and care**

Children with spina bifida assigned themselves more negative cards than their siblings ( $t=2.467$ ,  $p<0.01$ ). These cards were related to not liking themselves, and being stubborn. When asked for clarification most of the children referred to their difficulty in daily functioning:

‘I just have to sit around and wait for her [mum] to finish her work, then I can get out of the house’. Girl with spina bifida, 7 years old

‘I don’t want to do CIC [clean intermittent catheterization used for continence management], my mum says I have to learn to do it myself but it takes long and I just want to play. She says I am stubborn’ Boy with spina bifida, 10 years old

These statements relate to the lower number of ‘independence’ cards in terms of care (e.g. ‘who helps you to dress’) children with spina bifida gave themselves compared to their siblings ( $t=-3.775$ ,  $p<.001$ ). Mothers overall scored highest on the cards, revealing their importance to children in providing support across a range of activities. Children with spina bifida reported more support from younger siblings than did their siblings ( $t=2.266$ ,  $p<0.05$ ). As some of the children with spina bifida and their siblings explained:

‘My mum carries me to school; and comes to school to do CIC’ Boy with spina bifida 8 years old

‘I can’t dress myself, I can’t move my legs. I can put on a shirt, but the trousers I can’t. My brother has to help me.’ Boy with spina bifida 11 years old

‘I help my sister to fill her basin with water. My mum then puts her down in the bathroom and then she baths herself’. Younger sister of a girl with spina bifida 7 years old.

Children with spina bifida attributed less independence cards to ‘Nobody’ ( $t=3.837$ ,  $p<.001$ ) than did their siblings. The most common card which was given to ‘Nobody’ was ‘who likes to lift you?’ Children with spina bifida explained their need for support with mobility:

‘Sometimes I want to get out of my wheelchair and crawl around. If I have pressure sores my mum does not allow me. Then I get bored because I am too heavy to carry and I can’t move my wheelchair on my own, so then I am stuck where she parked me’. Girl with spina bifida 13 years old

## **Discussion**

Children’s perceptions of family were explored using the Family Relations Test to seek their views on family relationships, support, restrictions, and care. The adjustments we made to the tests helped us to successfully engage the children and administer the test in a culturally appropriate and understandable manner.

We identified the following key elements in family relationships, support and care:

- Mothers play a key role in the children’s lives, support and care
- Fathers are relatively absent for both children with spina bifida and their siblings
- Elder and younger siblings play an important role in the care and inclusion of children with spina bifida
- Other relatives are important in the care for children with spina bifida
- Children with spina bifida have more negative self-perceptions compared to their siblings

Mothers were given the highest average of positive feelings and recognition of support provided, of all relatives. The positive interaction and caring role did not differ for children with spina bifida and their siblings, and is applicable to most family settings. Children with spina bifida in our study did however perceive more negative interactions with their mothers than their siblings. It is likely that the increased amount of time spent with their mothers, due to their extensive

medical and rehabilitation care needs increases potential for negative interaction and frustration in the child-parent relationship compared to the sibling-parent relationship. Siblings may have fewer care needs and less time interacting with their mother. This finding is in line with studies in high income countries where spina bifida affects the parent-child relationship more negatively for mothers than for fathers, possibly due to the mothers' continuous exposure to spina bifida related demands (Vermaes et al., 2007). In Malaysia, dysfunctional parent-child interaction is higher if the mother is the sole caregiver (Kanaheeswari et al., 2011). In Canada, Antle et al. (2009) found that mothers are the most important source of support for children with spina bifida followed by fathers, siblings, and other family members. Despite higher negative interactions, overall relationships with mothers are positive and children feel close to them.

The low average number of cards given to fathers (positive and negative) by both children with spina bifida and their siblings in our study, could indicate children perceive their fathers to be less present in their lives. In an earlier study Shwalb et al. (2013) mentioned that traditionally the role of a father was one of authority and provision of household income for the family in sub-Saharan Africa. Mothers were typically considered to provide the direct physical and emotional care for children in this context (Lamb, 2004, Shwalb et al., 2013). Although society is changing, and some fathers are involved in the care for their children, the majority are less involved in direct care than mothers. An earlier study showed that whilst half of Ugandan fathers report to participate in childcare, on average they only spend 1 hour a day on this task (Nkwake, 2012).

In our study, we found grandmothers and elder siblings played important roles in the children's lives. Traditionally children in Uganda live with their extended families (Rutakumwa et al., 2015). Although family sizes have reduced, especially in urban areas, the presence of a grandparent, aunt, uncle or cousins in addition to the nuclear family is still common. Families in our study had an average of seven household members. In the families where mothers were absent, grandmothers and elder siblings would take up the care for the child with spina bifida. Grandmothers have played a key role in child care in Uganda over the past decades especially for children orphaned by AIDS (Rutakumwa et al., 2015).

In all families, elder siblings had a general responsibility for looking after younger siblings. In our observations, we noted elder siblings often take on a caring role in the home and school settings. In a previous study, we found siblings of all ages noted their sibling with spina bifida was treated differently in school and the community (Bannink et al., 2016b). Elder siblings in this study reported making an effort to include their sibling with spina bifida in daily and social activities. They often played an important role in getting the child to and from school. However, we found that children with spina bifida had less (positive and negative) feelings towards their elder siblings compared to their younger siblings. The children with spina bifida perceived more

positive relationships and support from their younger siblings. This could indicate that children with spina bifida have less interaction with their elder siblings, compared to their interactions with younger siblings in terms of play and equal relationships.

Elder siblings are more likely to have their own social interactions outside the home, and are often expected to help in household chores such as fetching water and going to the shop compared to younger siblings. Relationships with younger siblings were referred to in terms of play and hugs. As children with spina bifida are less mobile than their peers, they tend to spend more time at home, and interact with younger siblings more than their elder siblings do. Our findings indicate the importance of sibling relationships and the important role siblings play in day to day care and social inclusion of children with spina bifida. In care and support programs, the current focus is on parents, and could be expanded by including siblings to further strengthen positive interactions and support for children with spina bifida. This is in line with earlier findings of studies conducted in USA in which inclusion of siblings in support programs has been argued for (Bellin and Rice, 2009) (Lindsay, 2014).

Most children with spina bifida in our study included 'other' relatives and househelps in their family selection; siblings did not do this. Having a househelp or 'maid' is a common practice in Uganda's central regions where this study was conducted (UBOS, 2014). Househelps are often relatives of the parents, and are paid a very small amount of money. In our previous study of parental stress in parents of children with spina bifida in Uganda, parents pointed out that they often felt alone in taking care of their child and found it hard to meet all the care demands. This was moderated by receiving support from other adults (Bannink et al., 2016c). In this study children with spina bifida acknowledged the presence and role of other adults in their home: they are involved in the care for children with spina bifida on a daily basis. Not all families had other adults to support the main caregivers though. Other adults may be less present in the lives of the siblings as they have different care needs, and therefore not be perceived as a family member with whom they interact.

In comparing family perceptions of children with spina bifida and their siblings, we found children with spina bifida had a more negative perception of themselves than their siblings, and showed less independence in terms of self care. This is in line with studies from high income countries, which found lower self esteem and high dependence in children with spina bifida (Rofail et al., 2013) (Bellin and Rice, 2009). The challenges with independence are mostly caused by mobility challenges. The self-perception of children with spina bifida was negatively affected by not being able to participate in household tasks. In an earlier study, parents explained children were sometimes left out from larger family gatherings due to mobility problems

(Bannink et al., 2016b). In this study mobility and physical care such as continence management were mentioned too.

Children with spina bifida did report more support from ‘Nobody’ than their siblings, which raises a concern about the care they receive as they may not be receiving the help they need completing daily tasks such as dressing and bathing. Warf et al. (2011) earlier described finding situations of child neglect during home visits in the eastern region.

### Limitations

Our study was limited by a small non randomized but purposely selected sample size, and the small number of siblings we could involve. Family relationships are varied and fluid. Our findings capture the perceptions of children at a certain point in time. Larger studies with longitudinal assessments and in-depth sibling-to-sibling analysis are recommended to understand the way relationships evolve over time. We also acknowledge limitations of the FRT. The FRT does not have standard scores or norm groups. Due to the lack of standard scores and norm groups test reliability cannot be calculated, and results cannot be generalized.

It is difficult to develop a standard test to measure family relations given the variety in cultural practices and languages. Our aim was not to create a Luganda version of the test for use in Uganda, but rather use the FRT as a tool to enable discussion and understanding of children’s family perceptions in that country. The FRT has been criticized for its lack of robustness as a psychometric instrument (Parkin, 2001). Nevertheless we chose to use the FRT for our study as it is one of the few tools which would allow the child to express their perceptions of family relationships in an interactive and less direct manner than many other research methods. We believe this helped us to reduce socially desired answers which may have been more prevalent if using direct interviewing techniques alone.

The FRT is also open to criticism in disability studies for the use of the word ‘dependency’ which is associated with the outdated charity model of disability. In an effort to address this, we modified the language of ‘dependency’ cards to ‘independency’ cards, which reflects the language of the Convention of the Rights of Persons with Disabilities and provides room for interpretations of support and care within a socio-relational model of disability (Reindal, 2008).

### Conclusions

Family relationships, perceptions of self and independency, support and care of children with spina bifida in Uganda need to be understood within the cultural context. Our study shows the

internal family networks of children with spina bifida in Uganda are wide and varied and family relationships are characterized by support provided by mothers and elder siblings and househelps. The culturally adapted FRT was a helpful tool to assess family relations, support, and care from the children's perspective. In some cases, the dolls produced to represent family members were further utilized in counseling sessions conducted by the CBR worker. The combined use of the dolls as an assessment and therapy tool, was found to work well in the low resource setting in Uganda, and should be further explored in intervention programs and studies.

To further disability inclusive development, we argue for an extended family centered approach in health care and social services, in which the children with spina bifida, their parents (including the fathers), siblings and house-helps are included. Siblings play a key role in the day to day interaction and development of children with spina bifida; by promoting positive interaction and interdependence, children with spina bifida are more likely to be included in daily life activities, school, and communities. At the same time siblings need to be protected from taking on the sole responsibility for the care of their sibling with spina bifida. Although mothers are the target group for most care and support programs in Uganda, they require support from other adults too, and may benefit more from programs which engage others in caring for their child with spina bifida to reduce their sole care responsibility. We recommend programs in which mothers, fathers, siblings, and other household members are involved as family units, and interdependent relationships are promoted. Specific focus on helping fathers to become role models in child care and examples in their communities fighting for disability inclusive development are encouraged. House helps too need to be involved in community based rehabilitation trainings to ensure children with spina bifida are assisted in their daily care needs including continence management.

A balance of task division with interdependence is important to ensure all family members develop to their full potential and are cared for. By enabling families to form interdependent units, they can be examples for other families in their communities, and speak up about and ask for disability inclusive development in their communities and country.

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## References

- Antle, B. J., Montgomery, G. & Stapleford, C. 2009. The many layers of social support: capturing the voices of young people with spina bifida and their parents. *Health & social work, 34*, 97-106.
- Bannink, F., Fontaine, J., Idro, R. & van Hove, G. 2016a. Motor function, cognitive outcomes and schooling of children with spina bifida in Uganda. *Forthcoming*.
- Bannink, F., Idro, R. & van Hove, G. 2016b. 'I like to play with my friends' children with spina bifida and belonging in Uganda. *Social Inclusion, 4*, 14
- Bannink, F., Idro, R. & van Hove, G. 2016c. Parental stress and support of parents of children with spina bifida in Uganda *African Journal of Disability, 5*.
- Bannink, F., Stroeken, K., Idro, R. & van Hove, G. 2015. Community Knowledge, Beliefs, Attitudes, and Practices towards Children with Spina Bifida and Hydrocephalus in Uganda. *International Journal of Disability, Development and Education, 62*, 182-201.
- Bellin, M. H. & Rice, K. M. 2009. Individual, family, and peer factors associated with the quality of sibling relationships in families of youths with spina bifida. *J Fam Psychol, 23*, 39-47.
- Bene, E. & Anthony, J. 1985. *Family relations test: children's version*, NFER-Nelson Publishing Company Limited.
- Celestin-Westreich, S., Baardda, B. & Ponjaert-Kristoffersen, I. 1999. *Familie Relatie Test*. Amsterdam: Pearson Test Publishers.
- Coomer, R. A. 2013. The experiences of parents of children with mental disability regarding access to mental health care. *Afr J Psychiatry (Johannesbg)*, 16, 271-6.
- Dennis, M. & Barnes, M. A. 2010. The cognitive phenotype of spina bifida meningomyelocele. *Developmental Disabilities, 9*.
- Gona, J. K., Mung'ala-Odera, V., Newton, C. R. & Hartley, S. 2011. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child Care Health Dev, 37*, 175-83.
- Hartley, S., Ojwang, P., Baguwema, A., Damulira, M. & Chavuta, A. 2004. How do carers of disabled cope? The ugandan perspective. *Child: care, health and development. , 31*, 14.
- Holmbeck, G. N. & Devine, K. A. 2010. Psychosocial and family functioning in spina bifida. *Developmental disabilities research reviews, 16*, 40-46.
- Holmbeck, G. N., Gorey-Ferguson, L., Hudson, T., Sefeldt, T., Shapera, W., Turner, T. & Uhler, J. 1997. Maternal, Paternal, and Marital Functioning in Families of Preadolescents with Spina Bifida. *Journal of Pediatric Psychology, 22*, 167-181.
- Kanaheswari, Y., Razak, N. N., Chandran, V. & Ong, L. C. 2011. Predictors of parenting stress in mothers of children with spina bifida. *Spinal Cord, 49*, 376-80.
- Lamb, M. E. 2004. *The role of the father in child development*, John Wiley & Sons.
- Lindsay, S. 2014. A Qualitative Synthesis of Adolescents' Experiences of Living With Spina Bifida. *Qualitative Health Research, 24*, 1298-1309.
- Mertens, P. & Bannink, F. 2012. Interdisciplinary care for children with spina bifida in east and southern Africa. *Journal of Medicine and the Person, 10*, 129-135.
- Miles, M. 2006. Children with spina bifida and hydrocephalus in Africa: can medical, family and community resources improve the life chances? The Independent Living Institute.

- Nkwake, A. 2012. An Examination of Childcare Practices and Perceptions amongst Employed Ugandan Males and their Working Spouses in the Kampala and Mpigi Districts. Unpublished work. PhD Thesis. University of Cape Town.
- Northrup, H. & Volcik, K. A. 2000. Spina bifida and other neural tube defects. *Curr Probl Pediatr*, 30, 313-32.
- Paget, A., Mallewa, M., Chinguo, D., Mahebere-Chirambo, C. & Gladstone, M. 2015. "It means you are grounded" - caregivers' perspectives on the rehabilitation of children with neurodisability in Malawi. *Disabil Rehabil*, 1-12.
- Parkin, A. 2001. The Bene-Anthony Family Relations Test revisited: Directions in the assessment of children's perceptions of family relations. *British Journal of Medical Psychology*, 74: 323-349.
- Reindal, S. M. 2008. A social relational model of disability: a theoretical framework for special needs education? *European Journal of Special Needs Education*, 23(2), 135-146.
- Rofail, D., Maguire, L., Kissner, M., Colligs, A. & Abetz-Webb, L. 2013. A review of the social, psychological, and economic burdens experienced by people with spina bifida and their caregivers. *Neurology and therapy*, 2, 1-12.
- Rutakumwa, R., Zalwango, F., Richards, E. & Seeley, J. 2015. Exploring the care relationship between grandparents/older carers and children infected with HIV in south-western Uganda: implications for care for both the children and their older carers. *Int J Environ Res Public Health*, 12, 2120-34.
- Shwalb, D. W., Shwalb, B. J. & Lamb, M. E. 2013. *Fathers in cultural context*, Routledge.
- UBOS 2014. National Housing and Population Census 2012/13. Kampala: Uganda Bureau of Statistics.
- van't Veer, T., Meester, H., Poenaru, D., Kogei, A., Augenstein, K. & Bransford, R. 2008. Quality of life for families with spina bifida in Kenya. *Trop Doct*, 38, 160-2.
- Vermaes, I. P. R., Janssens, J. M. A. M. & Gerris, J. R. M. 2007. Parents' Social Adjustment in Families of Children with Spina Bifida: A Theory-driven Review. *Journal of Pediatric Psychology*, 32, 1214-1226.
- Vermaes, I. P. R., Janssens, J. M. A. M., Mullaart, R. A., Vinck, A. & Gerris, J. R. M. 2008. Parents' personality and parenting stress in families of children with spina bifida. *Child: Care, Health and Development*, 34, 665-674.
- Warf, B. C., Ondoma, S., Kulkarni, A., Donnelly, R., Ampeire, M., Akona, J., Kabachelor, C. R., Mulondo, R. & Nsubuga, B. K. 2009. Neurocognitive outcome and ventricular volume in children with myelomeningocele treated for hydrocephalus in Uganda. *J Neurosurg Pediatr*, 4, 564-70.
- Warf, B. C., Wright, E. J. & Kulkarni, A. V. 2011. Factors affecting survival of infants with myelomeningocele in southeastern Uganda. *J Neurosurg Pediatr*, 7, 127-33.

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