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Article

"I Like to Play with My Friends": Children with Spina Bifida and Belonging in Uganda

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Abstract
This paper describes experiences of living and belonging from the perspectives of Ugandan children with spina bifida and their siblings and parents. We explored belonging at micro, meso and macro level taking into consideration African Childhood Disability Studies, central concepts of family, cultural conceptions of disability, poverty, and the notion of 'ubuntu', and using child-friendly culturally adjusted interview methods including play. Whilst children with spina bifida had a strong sense of belonging at household level, they experienced more difficulties engaging in larger social networks, including school. Poverty and stigma were important barriers to inclusion. We propose strengthening the network at family level, where the environment is more enabling for the children to find a place of belonging and support, and expanding investment and awareness at community and national level.

Keywords
daily functioning, development assistance; disability; hydrocephalus; inclusive education; poverty; social discrimination; spina bifida; Uganda

Issue
This article is part of a regular issue of Social Inclusion, edited by Professor Ulf R. Hedetoft (University of Copenhagen, Denmark).

1. Background

1.1. African Childhood Disability Studies and Conceptions of Disability

Disability studies in sub-Saharan African countries have largely focused on adults with disabilities and caregivers of children with disabilities, and have primarily been conducted in South Africa. Children's narratives are absent in most disability literature (Curran & Runswick-Cole, 2014), and more so in African studies. Disability studies have argued for greater awareness and appreciation of diverse understandings of disability in low resource settings and highlighted the need for a different discourse (Grech, 2009; Meekosha, 2011; Seligman & Darling, 2009; Whyte, 1995).

Schalock (1997) argues that in cultures with an interdependent focus, acceptance in the group is a more significant contributory factor to quality of life than in independence or individualistically oriented cultures. Chataika and McKenzie (2013) build further on this, and explain that care and belonging may have a more prominent place than formal education and independence in the lives of African children with disabilities (Chataika & McKenzie, 2013). They suggest it is important that African Childhood Disability Studies explore family andcultural conceptions of disability, poverty, and the notion of 'ubuntu' ('I am because we are' or 'humanity to others').

Perceptions of impairment and disability are social

phenomena subjected to 'substantive temporal, cultural and situational variation' (Ingstad & Whyte, 1995). Social-anthropological and historical studies have described cultural and belief systems of disability in Africa (Braathen & Ingstad, 2006; Devlieger, 1998; Ingstad, 1999; Miles, 2002, 2004). Findings show a complex range of cultural concepts including the child being 'cursed', 'bringing misfortune',being a 'gift' or presenting a challenge to the family (Devlieger, 1998; Franzen, 1990; Wright, 1960). Chataika and McKenzie (2013) describe the complexity of disability concepts in Southern Africa, and point out how they are strongly associated with spiritual understandings of the nature of disability (Chataika & McKenzie, 2013).

In Uganda, the focus of this study, most dialects lack a single word that translates into the English word "disabled"; however all descriptions combine the notion of physical limitation and powerlessness (Lwanga-Ntale, 2003). The definition of disability in Ugandan laws and policy documents is not harmonized. The Persons with Disabilities (PWD) Act 2006 defines disability as 'a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation'. By recognizing that disability is the result of the interaction between impairment and external barriers, the PWD Act aligns the legal definition of disability in the Ugandan law to that enshrined in the Convention on the Rights of Persons with Disabilities (CRPD), which Uganda ratified in 2008 (Enable, 2015). However unlike the CRPD, the PWD Act requires that disability be substantive, which has implications for disability rights at a practical level (Ojok & Wormnæs, 2013). The Uganda Bureau of Statistics (UBOS) estimates 12.5% of the population in Uganda lives with a disability (UBOS, 2014). Discriminatory attitudes and behaviours, a gap in implementation of the regulatory framework, lack of coordination between government and civil society, and a fragmented programmatic approach all challenge the implementation of the CRPD in Uganda (UNICEF, 2014).

2. Children with Spina Bifida in Uganda

2.1. Spina Bifida

Spina bifida is a neural tube defect, a congenital abnormality causing disability, whereby the spinal cord and vertebrae do not form completely and the neural tube fails to develop normally. Worldwide incidence of spina bifida varies between 0.17 and 6.39 per 1000 live births (Bowman, Boshnjaku, & McLone, 2009; Kinasha & Manji, 2002; Msamati, Igbigbi, & Chisi, 2000; Shaer, Chescheir, & Schulkin, 2007). Incidence and prevalence rates in Uganda may be higher due to inadequate folate consumption by pregnant women (Bannink, Larok, Bauwens, Kirabira, & van Hove, 2015; Whyte, 1995) lack of pre-natal care (Miles, 2002), absence of secondary prevention services (Frey & Hauser, 2003), and higher exposure to environmental risk factors such as dioxins (Safi, Joyeux, & Chalouhi, 2012) and fumonisins intake (Hendricks, 1999; Marasas et al., 2004; Wild & Gong, 2010). Although Warf et al. estimate that 1,400 children are born with spina bifida in Uganda annually (Warf, Wright, & Kulkarni, 2011), no national data are available.

Most children with spina bifida have some degree of paralysis, which affects their mobility as well as bowel and bladder control (Northrup & Volcik, 2000; Verpoorten & Buyse, 2008). Sixty-six per cent of children with spina bifida in low-income countries develop hydrocephalus (Warf & Campbell, 2008).

In Uganda, concepts describing children with spina bifida vary by region. Descriptions often refer to the physical appearance of the child, e.g. 'swelling on the back' (*ekizimba mu mugongo* in the Central Region), 'the one with a split spine' (*owacwekire orukizi* in the Western Region) or to the secondary impairments a child may have, e.g. 'the one smelling of urine' (*langwece* in the Northern Region) for children with non-managed incontinence problems, or 'the one with the big head' (*baana be gimitwe migali* in the Eastern Region) for those with hydrocephalus (Bannink, Stroeken, Idro, & Van Hove, 2015).

2.2. Health and Rehabilitative Care

Most children born with spina bifida need surgery to close their back in order to prevent infections. Children with spina bifida and progressive hydrocephalus also often need surgery to prevent secondary impairments (IFSBH, 2014). Children with spina bifida experience mobility challenges and incontinence which affect their participation in daily activities, and require the use of assistive devices and continence management (Abresch, McDonald, Widman, McGinnis, & Hickey, 2007; Andren & Grimby, 2000; Danielsson et al., 2008; Jansen, Blokland, de Jong, Greving, & Poenaru, 2009).

Surgery and rehabilitative care is expensive and inaccessible for many children born with a disability in Africa. Their families are often their main source of care and protection (Guyer, 1981). Families living in poverty often struggle to find resources to provide this care and protection (Miles, 2002) as external and government support is limited (van der Mark & Verrest, 2014). In 1990, the Government of Uganda adopted Community Based Rehabilitation as a health service strategy to reach more persons with disabilities (NUDIPU, 2007). This strategy is still in place, but the efforts that arebeing made to provide basic services at community level for children with spina bifidaremain largely remain funded by international donors and charities (Mertens & Bannink, 2012).

At the time of this study, the initial surgery (closure of the spine) in Uganda was only available in two public government funded hospitals (Mulago National Refer-

ral Hospital in Kampala and Mbarara Regional Referral Hospital), and one private specialized neuro-paediatric hospital (CURE Children's Hospital) in Mbale, eastern Uganda. In north, west, and central Uganda three rehabilitation centers, funded by international donors and charities offered occupational therapy, physiotherapy, continence management, and social support services for children with spina bifida and their families (see Figure 1: Map).

2.3. Education

A special needs education department was created in the Ministry of Education in Uganda in 1973 (USDC, 2003). To date, government policies continue to promote special needs education and the establishment of special schools rather than inclusive education for children with intellectual disabilities (UNICEF, 2014). In a study on parental stress of 139 parents of children with spina bifida in Uganda, we found that more than half of the children with spina bifida were going to mainstream schools, none were going to special schools. Inclusion in these schools remained limited, with parents reporting discrimination, exclusion, and lack of services to manage incontinence at school for their children (Bannink, Idro, & Van Hove, 2016). Challenges with inclusion have been reported earlier in South Africa (Chataika, McKenzie, Swart, & Lyner-Cleophas, 2012). Disability grants are available for families with a disabled family member in South Africa. While these grants helped financially, they were not found to improve the education or employment outcomes of persons with disabilities (Loeb, Eide, Jelsma, Toni, & Maart, 2008).

2.4. Poverty

Persons with disabilities typically live in poorerthanaverage households (Emmett, 2006; Filmer, 2008; Lwanga-Ntale, 2003). Palmer further explains that most studies examine the income poverty rate of persons with disabilities, without taking into account the additional expenditure they incur which are attributable to their disability (Palmer, 2011). Looking after a child with spina bifida increases financial costs for families in the form of medical treatment, rehabilitation, and transport. It also has an indirect cost, by reducing the amount of time a parent is able to devote to income-generating activities, as many are directly involved in rehabilitation activities such as continence management. The monthly income of families in our study ranged from $28 to $689 with a median of $82 (income derived from all sources, including wages, market sales, cattle, land and other assets). This is much lower than the total national average of $156 (converted from Ugandan Shillings), though closer to the average rural income of $112 and related regional variations (UBOS, 2014). We found that looking after a child with spina bifida increased financial costs for families in terms of medical treatment, rehabilitation, and transport. Living in poverty may also have increased the risk of having a child with spina bifida in the first place, as the mother was unlikely to attend antenatal care, eat foods rich in folic acid or take supplements before and during her pregnancy, all of which could have prevented spina bifida.

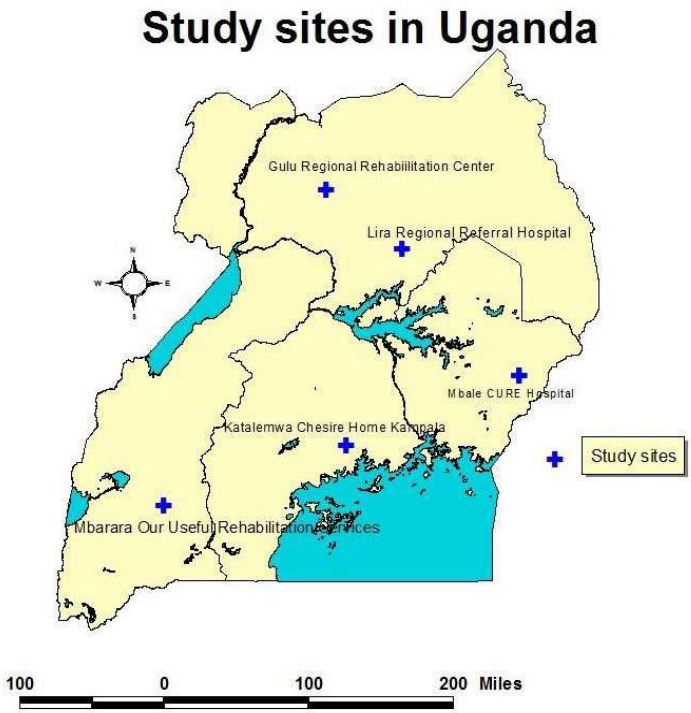

Figure 1. Map study sites.

In this paper we describe experiences of belonging and being of children with spina bifida and their families living in Uganda. Themes of belonging at micro, meso, and macro level were explored, taking family, friends, health care, school, and socio-economic factors into consideration.

3. Methods

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 of 8 years-old and above where possible. Consent forms were translated into the local languages and discussed and agreed with the participants, with assistance of a translator if the participant or child did not speak English.

In total, 139 families were recruited and 139 parents, 97 children with spina bifida, and 35 siblings between 4 and 14 years of age were interviewed. Due to lack of contact details, children could not be traced from medical files and databases of CURE and Mulago hospitals as initially planned. Therefore, purposeful sampling was used in Mbarara, Kampala, and Mbale where CURE holds bi-monthly clinics. CURE hospital and the partnering rehabilitation centers in Kampala and Mbarara were requested to list the children registered with spina bifida in their follow up programs, and inform them of the study during home visits and during reminder clinic attendance telephone calls. In Gulu and Lira, where no follow up system or registry of the children was in place at the time, radio announcements were aired to inform parents of the forthcoming review clinic in the area. The announcements specifically invited parents of children with spina bifida and hydrocephalus between the age of 4 and 14 years to attend.

Qualitative semi structured interviews, observations, and quantitative functioning scales measurements were combined and administered to 100 families at the clinic and 39 families at home between June 2011 and December 2014. The siblings interviewed were recruited during home visits, purposefully selecting the sibling closest in age to the child with spina bifida in the household. Observations were carried out during home visits and during clinic days. The clinic observations were held at least twice in each of the five sites during review days held specifically for children with spina bifida and hydrocephalus.

The semi-structured interviews contained questions about the child's family, home setting, their typical day, what they like and dislike, friendships, school, and health care. Ugandan-made dolls, drawing paper and colours for children were used during the interviews to help children open up and narrate their stories. E.g. when asking children about their family, children were encouraged to select a doll for each family member or draw their family and talk about them. The same approach was used to help children narrate stories about what other people would say to them e.g. at school, and to act out or draw situations which they enjoyed or disliked. The children enjoyed the interaction and were keen on visually demonstrating their family members and school setting.

In addition to the semi structured interviews, the Vineland Adaptive Behaviour Scales (VABS) Daily Functioning and Social Skills Sub Scales were administered by interviewing the parents and observing the children's abilities. The interviews with the children, siblings, and parents were held in the local language of the area, and a translator was hired and trained to assist in conducting the interviews, and observations. Some of the interviews were conducted in English, if parents or children were fluent and requested it.

The semi-structured interviews were not audio recorded, but answers were written out during the interviews and transcribed upon completion. Family set up and drawings were noted and kept. The interview data were analysed by thematic coding and analysis of the manuscripts using NVivo10. In this process, themes were identified representing experiences of children with spina bifida.

Handheld records for the questions of the VABS subscales were kept during interviews, and entered into a database after completion. The sub-total scores for each subscale were calculated to compare means of the scores of the children with spina bifida and their siblings using SPSS16. Observations on interactions and non-verbal communication were noted and checked with the text transcribed.

4. Results

4.1. Demographics

A total of 97 children, 35 siblings, and 139 parents out of 139 families with a child with spina bifida were interviewed. Table 1 describes the demographics of the study population. The mean age of the 82 male (59%) and 57 female (41%) children with spina bifida was 6.04, ranging from 4 to 14 years of age (SD=2.01). 55.9% of them were going to school: 36.8% (50) in nursery school, 16.2% (22) in primary school, and 2.9% (4) in secondary school.

Parents' ages ranged from 25 to 49 years, with an average age of 35.7 (SD 5.5). Mothers constituted the majority of the parental respondents, followed by fathers and grandmothers. Almost half of the respondents were farmers.

Of the 35 siblings interviewed, 40% were male and 60% female. The median age was 7.8, ranging from 4 to 14 years of age (SD=2.53). All of them were schooling; 25.7% (9) in primary, and 74.3% (26) in secondary school.

Table 1. Demographic characteristics of the study population (N=139 children, N=35 siblings)

Variable	Child	%	Sibling	%
Gender child				
Male	82	59.0%	14	40.00%
Female	57	41.0%	21	60.00%
Child is schooling in				
Nursery school	50	36.8%	0	
Primary school	22	16.2%	9	25.70%
Secondary school	4	2.9%	26	74.30%
Not schooling	60	44.1%	0	
Type of disability				
Spina bifida	76	54.0%	0	
Spina bifida and hydrocephalus	64	46.0%	0	
Location/region				
Central	65	46.8%	35	100%
East	26	18.7%	0	
West	29	20.9%	0	
North	19	13.7%	0	
Religion				
Christian	101	72.6%	32	80.0%
Muslim	26	18.1%	6	17.1%
Other	13	9.3%	1	2.9%
Relationship parent				
Mother	105	75.5%	26	74.3%
Father	17	12.2%	6	17.1%
Grandmother	10	7.2%	2	5.7%
Other	7	5.1%	1	2.9%
Education level parent				
None	6	4.5%	3	8.6%
Primary	75	56.4%	22	62.9%
Secondary	29	21.8%	6	17.1%
Vocational	12	9.0%	1	2.9%
University	11	8.3%	3	8.6%
Marital status parent				
Single	12	8.8%	0	
Married	103	75.2%	26	74.3%
Separated	11	8.0%	6	17.1%
Widowed	11	8.0%	3	8.6%
Monthly household income				
< 30 euro	25	18.8%	9	25.7%
30–60 euro	31	23.3%	10	28.6%
61–90 euro	28	21.1%	7	20.0%
> 90 euro	49	23.3%	9	25.7%
Occupation parent				
Finance / administration	4	3.0%	2	5.7%
Small scale private business	30	22.6%	7	20.0%
Teacher / education	8	5.6%	3	8.6%
Medical / paramedical	4	2.6%		
Technical / transport	10	7.1%	1	2.9%
Civil service / government	3	2.3%		
Peasant farmer	62	46.6%	19	54.3%
No occupation	13	9.8%	3	8.6%

Household size ranged from 2 to 13 with an average of 8 people per household. The average monthly household income was $82.

The majority (96.4%) of the 139 children with spina bifida in the study had undergone surgery to close their spine (myelomeningocele closure) earlier in life. Of the 64 children who had both spina bifida and hydrocephalus, 23 (35.9%) had undergone endoscopic third ventriculostomy while 12 (18.6%) had ventriculo-peritoneal shunts placed. Only 5 (3.6%) of all children in the study never had surgery. Most of the children (127 or 91.4%) received rehabilitation services such as physio- and occupational therapy.

Of the 139 childrenstudied, 136 (97.8%) could sit unaided and 64 (48.9%) could walk unaided. Of the 75 who could not walk unaided, 23 (30.6%) used a wheelchair, the same percentage used crutches, and 5 (0.7%) used other aids. In total 23 (16.5%) used no aids and crawled.

Over 85% of the children in our study were incontinent. Table 2 shows percentages of children using clean intermittent catheterization (CIC) and bowel management to manage their incontinence.

Table 2. Incontinence in children with spina bifida in Uganda (N=139).

	Yes	**No**
Child is continent of urine	15 (10.9%)	122 (89.1%)
Child uses clean intermittent catheterization	100 (78.2%)*	27 (21.3%)
Child is continent of stool	18 (13.1%)	119 (86.9%)
Child uses bowel management	92 (76.7%)**	28 (23.3%)

Notes: * 22 (22%) practices CIC without assistance of another person; ** 7 (7.6%) practices bowel management without assistance of another person.

Table 3. Vineland Adaptive Behaviour Daily Functioning and Social Skills Subscale Outcomes for children with spina bifida and siblings in Uganda (means, SD, and t-test).

Variable	**Children with SB**	**Siblings**	**Difference**
Daily functioning (Vineland) N=131	13.91 (5.1)	19.23 (2.1)	t=6.03 p<0.000
Social skills (Vineland) N=133	11.49 (1.8)	11.97 (0.2)	t=1.59 p=0.112

Table 3 shows parents' ratings on the Vineland Adaptive Behaviour subscales. Daily functioning tasks such as removing a jumper, drinking from a cup, face washing and hair brushing were achieved by most of the children, while other tasks which involve more movement were more challenging, e.g. fetching water and dressing independently (including trousers/skirts and shoes). Compared to siblings (N=35) in the same age group, the scores were significantly lower with a mean total subscale score of 13.9 (SD 5.1) for the children with spina bifida and 19.2 (SD 2.11) for their siblings (p<0.001). Social skills subscale scores of children with spina bifida were slightly but not significantly lower (11.49, SD 1.8) than those of siblings (11.97, SD 0.2).

4.2. My Home

When asked to describe their home, most of the children explained where they lived and who they lived with. In describing their families, most started by mentioning their parent(s), followed by their siblings and aunties or grandparents. Househelps were often referred to as 'aunts'. The majority of children also talked about their neighbours and physical environment.

> "There is a mango tree in our compound. When it is mango season, we eat a lot of mangoes. We sit in the shade and play games. I like playing meso [a board game] with my neighbor." (14-year-old boy with spina bifida, Central Uganda)
> "It's just me and my mum. We live in a hut. The neighbours are far. I sit outside under the tree when my mum is digging. Sometimes I do the dishes." (8-year-old boy with spina bifida and hydrocephalus, Northern Uganda)
> "This is my home. It is on a hill. I like to play there with my sister [points in the direction of the corner of the compound]. My grandmother looks after us. Most of the time I stay home." (10-year-old girl with spina bifida during home visit, Eastern Uganda)

The majority of the children participated in some of the common Ugandan daily household activities, such as doing the dishes, and washing clothes: "I like to wash plates. My sister gets water and then I wash." (7-year-old girl with spina bifida, Central Region). Other common household activities were more difficult for most, e.g. fetching water and sweeping the compound. Children with both spina bifida and hydrocephalus experienced greater difficulty in participating in daily household activities, as they tended to have relatively less developed motor skills.

> "His head is too heavy, he cannot balance well, he easily falls or knocks things, he cannot help in the house." (Parent of a 9-year-old boy with spina bifida and hydrocephalus)

Interactions observed during home visits showed how children are often allowed to participate and interact with others, but are not actively encouraged. Only a few parents made arrangements to improve accessibility in their compound, or encouraged their child to join others in play or household activities. Siblings often

helped the children with spina bifida by doing household activities such as washing together. In two observations, a sibling brought a jerrycan with water, and poured water in the basin for the child with spina bifida, so that they could then help in washing the clothes. Not being able to go and fetch water on their own was something children expressed sadness about:

> "I would like to go with my sisters and collect water, but it is not possible, they go and I am left at home, I cannot meet others on the road and talk about secret things like they do because I am always home." (12-year-old girl with spina bifida, Eastern Uganda)

In some homes, children were neglected and not encouraged to participate in daily household activities and games. The majority of the children were found sitting on a mat or outside on the bare ground when visited at home. This was more common for those with both spina bifida and hydrocephalus, who had more severe cognitive and motor skills difficulties.

The games children with spina bifida participated in were often board games or swinging. Occasionally a child would participate in a ball or tap game while crawling. Mostly children with spina bifida would be observers if siblings were playing games which required more movement. In some cases, they would not be allowed to play outside, mostly when they had pressure sores or infections.

> "I like to play outside but when I have a wound [pressure sore] I am not allowed to crawl and play outside, then I watch them from the house." (7-year-old boy with spina bifida)

Family events such as family meetings and prayers, weddings, funerals and memorials are often referred to as 'functions' in Uganda are an important part of family life. When asked about these 'functions', children and siblings explained that they attended church functions, and occasionally weddings or funerals, depending on the location and distance they would have to travel. Single parents said they found it challenging to attend events together with their child with spina bifida as some felt stigmatized by relatives and others at the events.

> "I went to the kwanjula [traditional wedding] of my aunt, it was here in the village, we enjoyed it." (Child with spina bifida, Central Region)
> "Sometimes our parents take us with them for functions, but if it is far we don't go." (Sibling of a child with spina bifida, Central Region)
> "Our family buries near our home, when there is a funeral, we are around. If it is far we don't go, I can't carry her and people will talk." (Mother of a child with spina bifida, Western Region)

4.3. My Friends

The majority of the children said they have at least one good friend, most of them said they have a number of friends, and play with neighbours and other children from their communities: "My best friend is Daniel [his neighbour, same age]. When he comes back from school we play together." (5-year-old boy with spina bifida, Central Uganda, not schooling), or "My friends are Sheila [sister] and Mariam [neighbour], we make homework together" (12-year-old girl with spina bifida, Central Uganda).

About a fifth of the children interviewed say other children sometimes verbally abuse them: "Children say that my head is big like a pumpkin" (12-year-old boy with spina bifida and hydrocephalus, Western Region), or "In my community the children abuse me, they call me mulema [lame]" (10-year-old girl with spina bifida from the Central Region).

Most of the children were shy in speaking to others or initiating play when observed in their home, school and clinic setting. During interviews, parents expressed their concern that while their children had friends close by home, e.g. neighbours and siblings, they had difficulties socializing in school and the wider community: "My child doesn't want to go far from home, they bully him about his big head." Siblings commented that their brothers or sisters have friends, but that sometimes other children call them names because of their disability: "Children who don't know her abuse her that she is cripple", and "Our friends don't allow my brother to play football with us because he uses crutches."

4.4. My Healthcare, Mobility and Continence

When asked about health care, children generally expressed excitement and happiness at attending rehabilitation services. Some differentiated between 'going to the local clinic' for general health issues, and going to their rehabilitation centres to see their occupational or physiotherapist. Most children knew the rehabilitation workers by name, and felt close to them. They described how the rehabilitation workers would visit them at home when they did not come to the clinic, and said they were happy to see them. A few children mentioned they did not like going to the general health facility, as the nurses often told them to go back to the rehabilitation center: "We cannot manage children with that condition here." Parents confirmed this, and explained that health workers appear anxious when they came to the clinic with their child for a malaria test or treatment of diarrhea or cough, and sometimes sent them back. The rehabilitation centers encourage families to attend general health services, as they do not provide this type of health care, but are focused on the disability specific rehabilitation only.

When asking about impairment-related difficulties,

the majority of children, siblings, and parents mentioned 'getting around' and practicing Clean Intermittent Catheterization (CIC) as the most stressful parts of their daily life.

4.5. Getting Around

For children with mobility challenges, all the children, siblings and parents interviewed mentioned the difficulty getting around. A third of the children who could not walk did not have access to an assistive device. Those who did possess aids said they often crawled at home, and in places where their wheelchair cannot access public spaces. Some children who lived in hilly geographical areas said there was no point in having a wheelchair.

> "I don't like using my wheelchair at home, there is no space in the house, and outside there are the gardens, we live on a hill, it's easier to crawl, especially in the rain season. I leave the wheelchair at a shop down at the main road." (8-year-old girl, Western Uganda)

Almost half of the wheelchair users could use the wheelchair on their own. However, they reported that they often needed help on the roads as these were full of potholes and humps, which made it very difficult for them to move without another person. Siblings often assisted their brother or sister to go to school or other places.

> "I would like to go to school by myself but it is not possible, I cannot cross the road near school, there is a deep ditch and many potholes, my wheelchair gets stuck, someone needs to push me." (12-year-old boy with spina bifida, Central Uganda)

Most of the younger children were carried by their mothers when travelling. Parents explained that this made it hard to move long distances, as the children can be quite heavy, and are not easy to carry. Nevertheless, many parents continued to travel in this way, as there was no alternative and they wanted their child to go to school or the rehabilitation center.

> "I have no choice, the wheelchair my child has cannot pass the road we take home, it is big, it is for adults, someone gave it to us. We leave the wheelchair at school, and I carry her on my back. I walk for almost one hour. I cannot change the school because here they understand her, and help her. Other schools have refused her to enroll. I cannot afford to use public transport, I would have to pay for both of us and the wheelchair. Passengers may complain about having a disabled on board and having to wait for the wheelchair to be loaded into the vehicle too." (Mother of a 7-year-old girl with spina bifida and hydrocephalus, Central Uganda)

Siblings indicated they felt responsible for their brother or sister since they were using a wheelchair and often needed their help to get around. Whilst most of them referred positively to helping out, some said they preferred to go somewhere alone, so they did not have to watch their sibling and make sure they are ok. Others indicated that the wheelchair or tricycle was helpful because they could carry things on it.

> "I always push my sister to school. It's heavy and the dust makes it hard to push her [in the dry season]. But the rainy season is worse, sometimes she has to stay home, because the wheelchair cannot pass the road." (12-year-old sibling of a 9-year-old girl with spina bifida)
>
> "My mother always tells me to take my brother with me but if I go around with him people look at us and call him names because he has a big head. I don't like that. I want to just meet with my friends alone." (14-year-old sibling of an 8-year-old boy with spina bifida and hydrocephalus)
>
> "I have to help my sister to get to the main road because there is a ditch she can't pass on her own. Her tricycle is good for fetching water, we can carry the jerrycans on it." (9-year-old sister to a 14-year-old girl with spina bifida)

4.6. Incontinence

All children and parents said incontinence is a big challenge to them. The siblings interviewed were not engaged in continence management, but did say it was sometimes difficult to find a space for their brother or sister to practice CIC. Whilst most of the children explained they got used to practicing CIC and bowel management, it still interfered with their daily functioning. Most explained it was easier when at home. When travelling or at school or other places, it could be very difficult to find an appropriate place and water to practice CIC or bowel management.

> "My child cannot use a normal latrine, they are often dirty, there is no space to do CIC or water to wash. Sometimes we just have to do it outside behind the latrine." (Mother to a 4-year-old girl with spina bifida, Eastern Uganda)

Some of the older children who practice by themselves say it interrupts their class, as the time they need to practice CIC does not always match with break times. They said it was hard explaining the need to go at certain times to their teachers and classmates. However, if children had enrolled and stayed in the same school over a longer period of time, they felt teachers and

students started understanding their needs better.

> "I have to get out of class to do CIC, it is not easy, I miss part of the lesson, and it took long for my friends to understand that I had to go out, they thought I was just dodging." (13-year-old girl with spina bifida in Western Uganda)

4.7. My School

Just over half of the children are in school, yet all are in the school going age. All 35 siblings in the similar age range were in school. Some of the children with spina bifida dropped out of school because of bullying: "I dropped out of school because my hands shake, I cannot write, they said I was stupid." (8-year-old boy with spina bifida and hydrocephalus, Northern Region).

Others did not get a school place, as no school in their area would accept them: "I went to five primary schools. No one wanted my child, they said they cannot manage disabled children." (Mother of a child with spina bifida, Eastern Region). Other parents said they did not have the finances to send all their children to school, and therefore preferred to select the ones without a disability as they would be more likely to complete their school successfully and find employment later:

> "I have 7 children and I can afford to send 4 to school. I cannot send her [the child with spina bifida], I have to add transport for her too as she cannot walk to school, and it is unlikely someone will give her job when she finishes." (Parent of a 5-year-old girl with spina bifida, Eastern Uganda)

Many parents also felt their child with spina bifida would be dependent on them the rest of their lives, yet children themselves had dreams about what they would to be in future: "I want to be a teacher" (7-year-old girl with spina bifida, Central Uganda). "I want to be a doctor so I can make people better" (10-year-old boy with spina bifida and hydrocephalus, Northern Uganda), and "I will become a lawyer so I can make sure all children with disabilities go to school." (12-year-old girl with spina bifida, Western Uganda). Other parents said their child could not manage school because their brain had been affected by their illness and the schools could not accommodate them.

Most of the children who were in school, said they enjoyed it: "My teacher is nice, she helps me and she tells stories." (6-year-old girl with spina bifida, Eastern Uganda). They have made friends, though are not able to participate in some subjects such as physical education (PE): "They carry me to play with them outside. Sometimes they say I cannot do something because I am disabled." (8-year-old girl with spina bifida, Central Region). Her sibling confirmed this: "She is doing well at school but they don't let her to do PE because they think she cannot do sports".

Children and parents rated their performance in school as average. Some complained of secondary disabilities which hindered their performance, such as poor eye sight and difficulties in writing. None of the children had ever been assessed for cognitive functioning.

4.8. What I Enjoy Most

When asked to tell a story about something which happened that the child enjoyed and made him or her feel happy, the majority narrated situations in which they were playing with their siblings or friends in the neighbourhood:

> "When I was playing hide and seek with my friends. I found the best hiding place under a bush and they could not find me." (5-year-old boy with spina bifida, Western Region)

Some mentioned going to church or special days such as Christmas when they got new clothes:

> "I like going to church with my mum and my sister, they have Sunday school and we sing songs and the teacher tells us stories about Jesus. It makes me very happy." (7-year-old girl with spina bifida, Eastern Region)

A few older ones mentioned situations at school in which they did well in exams or got a compliment from the teacher:

> "One day I had a math test. I find mathematics very difficult and usually I fail, but I worked very hard, and this time I passed. I was very happy, and my teacher said I had done a good job." (13-year-old boy with spina bifida, Central Region)

Siblings often mentioned games their brother or sister enjoyed playing, and mentioned things they would do together. Parents described similar activities and explained how their children are less clingy and more comfortable at home.

> "At home we are at peace. Nobody looks at us, no one calls us names. We just get on with what we need to do. She is calm when she is home, I can put her down and she doesn't cry." (Mother to a 4-year-old girl with spina bifida and hydrocephalus, Northern Uganda)

4.9. What I Don't Like

When asked to tell a story about something which happened that the child did not like and made him or

her feel sad or angry, the majority narrated situations in which they were called names, had a fight with their sibling or friend, or were not allowed to play with others.

Parents explained that their children were often anxious in social situations and public places, and were clingier compared to their siblings, e.g.: "I cannot leave her with anyone, she needs me, I always have to be around, she fears people". A few siblings made similar statements such as "She doesn't want to be alone when we go somewhere, I have to stay close to her".

Similar observations were made during the interviews, in which many children were initially nervous and clingy and stayed very close to their parent(s). A few of them were able to express their fear verbally, as with this 9-year-old boy with spina bifida from the Northern Region: "I don't want to go somewhere without my mum, people say bad things".

Although not expressed directly by all children, most of them did seem to have a (negative) awareness of their impairment following comments made by other people. This was illustrated by statements about preferring to be at home, and avoiding or being anxious in larger public settings, and was observed during home and clinic visits. A few older children mentioned they would like to be treated the same way that children who do not have spina bifida are treated.

5. Discussion

Children with spina bifida in this study had a strong sense of belonging at household level, but experienced more difficulties in engaging in wider social networks including school. A discussion of belonging divided in thematic areas of family (micro), community (meso), and poverty, services and policy (macro) level is outlined below.

5.1. Micro—Family Level

Belonging to a family is a central and key concept in African societies (Bigombe & Khadiagala, 2003; Chataika & McKenzie, 2013; Guyer, 1981; Malinowski, 1929). In our study, children described their households as extended family units, often including not only direct relatives such as parents, siblings, aunts, uncles, and grandparents, but also house helps and neighbours. Whilst some of the children stayed alone with one parent, the majority lived in larger households of about 8 members. Children, siblings and parents described daily activities, play and interactions in and around their home compounds in which they were all involved. Participation in household activities is a key part of daily life and belonging in the Ugandan home setting. Children are often expected to assist in chores such as fetching water, washing clothes, dishes, and sweeping the compound. Children who participated in doing the dishes and washing clothes expressed a sense of accomplishment in this. The daily household activities provided social interaction between siblings and neighbouring children. Children in our study expressed sadness about not being able to participate in fetching water.

Interviews with siblings and parents confirmed the same. Parents' ratings on the VABS daily sub-scale showed that children with spina bifida had more difficulties in daily functioning than their siblings. The lower scores could be explained by mobility challenges, lack of assistive devices and poor infrastructure. This is in line with findings from high income countries where physical wellbeing and functioning were significantly lower in children with spina bifida as the disease affects ambulation, functional mobility and self-care (Abresch et al., 2007; Danielsson et al., 2008; Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009).

In cases of more severe disabling impairments, we noted that children were less involved and had less interaction with household members. When not participating in an activity, most children sat outside under the shade of a tree or, if living in a larger urban environment, inside, watching what others were doing. A number of children with spina bifida appeared neglected, malnourished, smelling of urine and in very dirty cloths. Warf, Wright et al earlier described finding situations of child neglect during home visits in the Eastern Region (Warf et al., 2011).

Children and siblings said that they participated in family events such as church functions, weddings, and funerals. Some parents explained that participation in these activities was sometimes challenging due to limited mobility and negative attitudes, which is in line with earlier findings of the authors (Bannink, Stroeken, et al., 2015).

5.2. Meso—Community Level

Most children describe a mix of experiences of acceptance and enjoyment of play with their friends, and being called names or bullied by others. Bullying and being stared at affected children's self-esteem and increased their anxiety, as we noted during interviews.

In the area of health and rehabilitative care, children said that they liked their rehabilitation worker, usually an occupational or physiotherapist, but described negative experiences with accessing general health care facilities. Children, siblings, and parents all cited mobility and continence management as challenges for participation in the community. These challenges have also been pointed out in other studies in high and low income countries (Kabzems & Chimedza, 2002; Martin, White, & Meltzer, 1989; Smith, Murray, Yousafzai, & Kasonka, 2004).

More than half of the children were going to school and enjoyed doing so. Inclusion physical education and accommodation of secondary disabilities which affect

learning was challenging. Some parents were financially unable to send their child to school; the child with spina bifida was unlikely to go to school till all other siblings were in school, as parents expected the child with spina bifida would be less likely to complete school successfully and be employed later.

Most children in our study had at times experienced negative attitudes, verbal abuse, as had their siblings and parents. This left the children feeling unable to participate, and made some of them avoid or feel anxious about going to school and public places. Other children were able to develop a sense of belonging at school. Our study did not look at bullying over time. It is expected that as a child participates in school for a longer period of time and can "prove" he or she is able to do the same or similar activities as other children, attitudes and behavior of classmates and parents change. We noticed this when studying community attitudes and behavior over time as described by parents (Bannink, Stroeken, et al., 2015). In wider public settings, this may need more awareness raising and behavior change.

In high income countries, children with spina bifida faced more social skills and inclusion challenges than their peers (Wyszynski, 2006), and had lower social integration regardless of whether they could ambulate or use wheelchairs (Dicianno et al., 2009). Our study also found that access to assistive devices did not necessarily make ambulation or social inclusion easier.

5.3. Macro—Poverty and Services

5.3.1. Poverty

The monthly income of families in our study ranged from 28 to 689 US dollars with a median of $82 (income derived from all sources includes wages, market sales, cattle, land and other assets), which is much lower than the total national average of $156 (converted from Ugandan shillings), though closer to the average rural income of $112 and related regional variations (UBOS, 2014).

Whilst poverty was not mentioned directly by participants, the reality of living in a low resource community affected participation in our study population. For example, feeling sad about not being able to fetch water would not have been an issue if running water were available in the home, or the water point could be easily accessed by a wheelchair Educational access for children with spina bifida is affected when parents can only afford to send 3 out of 5 children to school: the child with spina bifida is unlikely to be selected, as they may have secondary disabilities which make learning more difficult, while it may cost more to transport them to school than would be the case for children who can walk or bike to school on their own.

Witter and Bukokhe (2004) found earlier that "They [Ugandan children] have a positive view of their own potential role in mitigating poverty, and are highly critical of the current performance of local government". The children in our study did not speak about the role of the government. However, they spoke about wanting to enter professions in which they could help other children with disabilities access education and health care.

5.3.2. Services

None of the families spoke about the CRPD which Uganda ratified (UN, 2006). Parents, neighbours, and teachers were mentioned as making the biggest difference and helping out in the inclusion of children in their communities. Reference was made to kindness of others and humanity (e.g. 'obuntu bulamu' in the Central Region), in line with the key concept of 'ubuntu' in the African setting. Access to formal systems such as public rehabilitative and social services were not mentioned in our study.

Lack of an enabling environment hindered children's participation. The children experienced their impairments as being restrictive. Their experience of the world with their impaired body (Campbell, 2009; Hughes, 2007) and perception of their body prevented them from engaging in daily activities such as fetching water, going to school, or play, which they saw as a missed opportunity to socialize. Some pointed out that assistive technology could be a burden when living in a hilly place. It is hard to imagine a parent or child living in a rural hilly area without roads arguing for a rights-based approach and the right to assistive devices for their child given that the entire population in the area lives in poverty, with limited access to health care, education, and has no running water.

In a study in South Africa, physical access, transport and medical information, and training and supporting teachers to respond to particular learning disabilities were identified as key areas that need to be addressed to allow children with disabilities to participate in the existing education system (Vosloo, 2009). A study in Uganda showed that children with disabilities are admitted without proper assessment of their educational needs, and resources are not available to provide them with an appropriate range of experiences (Kristensen, Omagor-Loican, Onen, & Okot, 2006). This is something that parents in our study referred to as well. Implementation of inclusive education is negatively affected by non-supportive attitudes of parents and community members, distance to school, unconducive school environment (access, materials, equipment), and lack of trained special need teachers (Abosi & Koay, 2008).

6. Limitations

Our study was limited to involving children who were receiving or attending follow up and rehabilitation

care, and were able to speak. Comparing regional differences was limited by the low numbers of children with spina bifida found in Northern Uganda. Here a 22-year long conflict between the Government of Uganda and the Lord Resistance Army displaced over 90% of the population. Persons with disabilities often faced severe mobility and sanitation challenges in the camp (Muyinda & Whyte, 2011). Whilst some persons received assistance (Mbazzi, Lorschiedter, Hollyne & Opok, 2009) those with congenital disabilities such as spina bifida were less likely to receive services living in a conflict zone compared to those living in poverty in other areas of the country. This may explain the low number of children found in the northern region, as few were able to survive without the initial surgery.

The presentation of a 'voice' is time and space bound (Mazzei, 2016). We were unable to present an ontological voice in which past, present and future were united. However, we did attempt to present voices of the children, their siblings and parents their parents, partly representing an enactment of forces. We took into account observations, and used nonverbal interview methods such as play and drawing. We were limited by translating these into verbal language (Tisdall, 2012). Children could not be included as researchers in this study, resulting in the expert-child bias in interpretation of the text and nonverbal communication (Tisdall, 2012). However, we worked with support groups of parents of children with spina bifida to contextualize findings and checked interpretations with expert parents and rehabilitation workers.

7. Recommendations

In line with Chataika and McKenzie (2013), our findings support African Childhood Disability Studies in which family, cultural conceptions of disability, poverty, and the notion of 'ubuntu' are central concepts. We advocate working with children in their home setting, where belonging is felt. Family members and peers also play an important role in advocacy and agency in order for belonging to be experienced in the community and school settings.

Rather than employing a child rights based approach, we argue for a family based approach, in which interventions include relatives, start from home, and focus on supporting the family network. Instead of autonomy, interdependency is key in the lives of children with spina bifida. By having expert parents, siblings, and children, families can argue for better services and discuss their needs with health care workers and schools. Through self-advocacy, in which the self is defined in relation to others and humanity to others, rather than in relation to an individual, attitudes and practices of community members can change over time.

Key interventions requiring implementation at the national level include poverty alleviation strategies, improvement of general health care, community based rehabilitation services and better access to education. Inclusion does not and cannot exist in a dysfunctional system of services based on right based policies which are not implemented. Critical analysis is needed of how to implement ratified conventions and policies in the Ugandan context, to make them applicable and useful.

8. Conclusion

This study contributes to African Childhood Disability Studies by describing how children with spina bifida and their families experience their daily life and create a sense of belonging in Uganda.

Provision of neurosurgery, rehabilitation, and assistive devices are key services which should be provided and certainly remove certain barriers. However, attitudes and the strong perception of having to 'fit in' the able bodied society (Campbell, 2009) still override the possibilities of children being included in their wider communities. Children mainly belong in their families; 'obuntu' or 'ubuntu' (Chataika & McKenzie, 2013) is key and is felt at micro level. We argue for building onto a network at micro level where the environment is more enabling for the children to find a place of belonging and support, and expand this at meso and macro level in support interventions for children in low-resource settings. A bottom up approach is needed to shift the paradigm at meso and macro level from an approach of excluding children with disabilities or making them 'fit in' the norm, to valuing them as unique persons with a sense of belonging and ability to create a society in which they are considered as participants and actors of change.

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Conflict of Interests

The authors declare no conflict of interests.

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