

# Availability and Uptake of Community-Based Rehabilitation and Inclusive Development Services in Southwestern Uganda: Experiences of Children with Spina Bifida, Caretakers and Health Professionals

Ambrose Ganshanga

OURS SHIP, Ruharo Hospital

Justus Asasira (✉ [asasirajsts@gmail.com](mailto:asasirajsts@gmail.com))

Mbarara University of Science and Technology <https://orcid.org/0000-0003-3924-0880>

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## Research

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# Abstract

It is over a decade since services for children with Spina bifida were established in Uganda which has increased the survival rate after spina bifida repair through follow ups. Such children have significant disability and other complications which damage the central nervous system. The consequences of this are more profound in low-income countries if post-operative and long-term care interventions are not adhered to. This study explored the availability and uptake of community-based rehabilitation and inclusive development services to children with Spina bifida in Southwestern Uganda.

## Introduction

Spina bifida is a neuro tube congenital defect (NTDs) in which the spina column is imperfectly closed in early pregnancy (during the 4<sup>th</sup> week) so that part of the meninges or spinal cord do not form normally resulting into nerve damage, permanent disability and other neurological disorders, (Northrup & Volcik, 2000; Xu et al., 2018). Spina bifida can be surgically closed after birth, but this does not restore normal function in the affected child due to varying levels of abnormalities and complications (Warf et al., 2011).

Globally, birth defects are a leading cause of death in the first year of life, and, for infants who survive there is an increased risk for long-term disabilities (Warf et al., 2011; Vellozzi and Sneisek, 2014). Although prevalence estimates for birth defects and their related disabilities can vary by source and are often dependent on what conditions are included and how they are defined, the World Health Organization (WHO) estimates that, globally, birth defects affect an estimated 1 in 33 infants, result in 3.2 million birth defect-related disabilities every year, and account for an estimated 270,000 newborn deaths yearly (Flores et al., 2014; ). The neural tube defects (NTDs) are the most common form of birth defects world over, although published data on Sub-Saharan African remains limited (Xu et al., 2018; Zangajor et al., 2016).

Neural tube defects (NTDs), serious birth defects of the brain and spine usually resulting in death or paralysis, affect an estimated 300,000 births each year worldwide (Zanganjor et al., 2016). Although the majority of NTDs are preventable with adequate folic acid consumption during the preconception period and throughout the first few weeks of gestation, many populations, in particular those in low and middle resource settings do not have access to fortified foods or vitamin supplements containing folic acid (Xu et al., 2018). Further, accurate birth defects surveillance data, which could help inform mandatory fortification and other NTD prevention initiatives, are lacking in many of these settings especially in Sub-Saharan Africa (Holmbeck and Devine, 2010; Warf, 2011; Flore et al., 2014; Eke et al., 2016).

Challenges faced by children with Spina bifida range from mild to severe depending on the location of the lesion on the spine and the amount of nerve damage involved (International Federation of Spina bifida and Hydrocephalus, 2014). However, the likely complications which affect people with Spina bifida are influenced by a number of factors for instance cultural beliefs, poverty, lack of proper treatment, stigma to both patients and caregivers (Djientchue et al., 2008). Although care for individuals with Spina bifida in

the developed world has changed substantially in the recent years and major advances in medicine and long-term care have led to improved survival and outcomes (Houtrow 2014), treatment outcomes in under developed countries remain poor with high early mortality (Holmbeck and Devine, 2010; Sims-Willaims et al., 2016). Neuropathic bladder management, intermittent catheterization, rehabilitation, psychosocial support to families and access to other services in addition to development of advances in medicine have had a positive impact of the quality of life of people living with Spina bifida (Boryskowski et al., 2004). Problems related to incontinence in Spina bifida have been managed through clean intermittent catheterization (CIC) and bowel wash out management techniques. The practices improve social continence and protect renal system from deterioration (International Federation of Spina bifida and Hydrocephalus, 2014).

Research on family functioning and psychosocial adjustment of families of children with Spina bifida in high income countries support a resilience-disruption view of family functioning, whereby the presence of a child with spina bifida disrupts normative family functioning at first, but after the period of time families adapt (Vermaes, Gerris, & Janssens, 2007). This is attributed to social support structures unlike in underdeveloped countries where Stress levels of parents of children with Spina bifida are higher (Holmbeck et al, 2010)

At the regional level, the treatment of neuro tube defects presents challenges on numerous levels including logistical and infrastructural barriers which stand in the way of delivering inclusive development services. Children are neglected and this affects their participation in daily life activities. (Danielsson et al., 2008).

The Uganda Bureau of Statistics estimates that 12.5% of the population has a disability, which translates to 2.7 million children living with some form of disability. It should be noted that over 18% of the children below 10 years of age live with severe disability in Uganda (UBOS, 2014; National Population Council, 2019). Uganda has got a legal framework that promotes the rights of people with disabilities and their inclusion. These include, persons with disabilities Act 2006, which provides for elimination of all forms of discrimination, Convention of rights of persons with disabilities (rectified on 55<sup>th</sup> September 2000), and equal opportunities Act (2007). Uganda has a strong disability movement and National Disabled Peoples Union (NUDIPU), and Uganda Society for Disabled Children (USDC). Uganda adopted Community Based Rehabilitation (CBR)-a health service strategy for reaching out to persons with disabilities in 1990. Despite the laws and policies being in place, they remain shelved with little being implemented. Where there has been some impact as far as protecting the rights and inclusion, the programs have majorly concentrated on adults with disabilities. Community based Rehabilitation programs are implemented by non-governmental organizations and private facilities making them less accessible to all children in need (UNICEF, 2014). Specific for neuro tube defects, national data is not available. It is estimated that 1,000 children are born with Spina bifida while over 2,500 children suffer from acquired hydrocephalus annually in Uganda (Warf et al., 2011). CURE Hospital of Uganda estimates that between 800 and 1,000 children in Uganda are born with Spina bifida defect each year (CURE Hospital, 2015).

Spina bifida program evaluation for South western Uganda show high levels of neglect of growing children with neuro tube defects, increased stress levels among parents, fathers abandon care roles to mother and the latter have increased the rate of divorce (Warf et al., 2011). The study further shows that 47% of children with neuro tube defects in western Uganda died before their fifth birth day while the remaining 53% of the affected children are neglected and abandoned in homes as their siblings go to schools, which affect their quality of life. The children with Spina bifida continue to suffer secondary disabilities, exclusion from social settings and remain at high risk of early mortality. Poverty also continues to affect access to services for children with disabilities (Xu et al., 2018; Bannink et al, 2015; Lwanga-Ntale, 2003; Miles, 2002). Children with Spina bifida and Hydrocephalus remain largely marginalized, their families are disproportionately poorer, most are unable to access schools and have higher rates of mortality (Emmett, 2006). Parents and care givers of children with Spina bifida have high stress levels and high level of dysfunctional interaction between parents, neglecting all care responsibilities to mothers (Femke, 2016).

In Uganda and sub-Saharan Africa disability studies have largely focused on access to initial medical care while others largely focus on programs for adults. Children narratives are absent in most disability literature (Curran & Runswick-Cole, 2014). For neuro tube defects like Spina bifida their effects are far much reaching as far as the development of their community. Therefore, Spina bifida is not only a public health issue but also a human rights and development issue. There for this study is intended to explore and measure the significance of availability and uptake of inclusive development services in relation to factors that influence the quality of life of children with Spina bifida. The study further examined inclusive development services under two perspectives, specialized interdisciplinary care services and community based inclusive services, an area that has not been explored in the existing literature.

## **Theoretical review**

Studies reveal that Spina bifida can be surgically closed after birth, but this does not restore normal function in the affected child due to varying levels of abnormalities and complications (Sims-Williams et al., 2016). Most children with Spina bifida have some degree of paralysis and sensory loss which affects mobility, difficulty with bladder and bowel control, Hydrocephalus accompanied by some level of brain damage (Walf 2012; Kahle et al., 2016). Health related quality of life (HRQOL) measures an individual's perception of how a chronic health condition (CHC) impacts on his or her physical or psychosocial functioning (Bakaniene et al., 2016).

Individuals with Spina bifida have multiple medical issues, impairments, decreased activity levels, and reduced functional health throughout their lifespan and therefore, require intervention from a multidisciplinary medical team (Kirpalani et al., 2010; Sims-Williams et al., 2016; Xu et al., 2018). The literature is mixed regarding a positive or negative relationship between the level and HRQOL for these individuals and what demographics may affect quality of life. In this study the quality of life was measured using International Classification of Functioning (ICF), disability and health which is the WHO framework for measuring health and disability as the functioning and disability.

There has been a growing call for “inclusive development” to meet contemporary development needs and challenges (Samans, 2017). This is a development approach that encompasses an agenda beyond growth and income is needed to ensure that the benefits of growth are shared equitably across all parts of society, particularly large groups of vulnerable poor populations. Although inclusive development is gradually finding its way in the development discourse, its ascendancy has not been accompanied with great conceptual clarity. While most Sub-Saharan African countries have registered high and sustained economic growth over the past decade, a large number of poor and vulnerable people have remained exclusive from the benefits of this progress than in any other part of the world (Van Gent, 2017).

Availability and access to specialized health care remains a challenge, in addition to attitudinal barriers, poverty, lack of implementation of rectified United Nations Convention of the Rights of persons with disabilities and convention of the Rights of Child (1989), and inadequate community social services for children with Spina bifida all affects their inclusion (Femke 2016).

Most studies have demonstrated that promoting inclusive development where Children with spina bifida are included in social, political and economic processes for increased human wellbeing, social and environmental sustainability, and empowerment is a far more powerful determinant of the quality of life of children with Spina Bifida. (Gupta et al., 2015). This study focused on measuring of specific contextual factors where the existing literature does not them indicate significance on the quality of life of children with Spina bifida.

As services for Spina bifida continue to advance, life expectancy and quality of life for individuals with spina bifida also improve and individuals continue to age into adulthood. It is imperative not only to attend to medical condition but also function and social issues facing the growing spina bifida population for improved lives (Houtrow, 2014).

In a study conducted in Uganda, on the quality of children with spina bifida, findings indicate that enhancing investment in community-based rehabilitation, continence management and discussion of family planning with families as part of holistic care improves the quality of life of spina bifida children. Stakeholders must have information and put these factors into consideration to design services that can improve the quality of life of children with Spina bifida (Sims-Williams 2017).

By October 2018, CURE hospital had operated 1,323 children with Spina bifida and Hydrocephalus in 2018 alone (Tim Erickson, Executive Director CURE hospital, 25<sup>th</sup> October, 2018). Ruth Nalugya, the Chairperson of National Spina bifida Association in a policy brief document presented to the minister of Health during the Commemoration, “the absence of facilities at the regional and district hospitals makes the treatment of Spina bifida and Hydrocephalus children more costly and increases congestion at CURE Hospital and OURS Center in Mbarara, KCH in Kampala and Gulu AVIS Center in the North. Due to negligence by health workers, all children are referred to the above centers, even when they have manageable infections. Parents who cannot manage have given up while most children have lost their lives”. (The New Vision, November 12, 2018).

Femke et al., (2016) further explain that parents of children with Spina bifida experience high levels of stress which affects care for a child with Spina bifida. To overcome this stress rehabilitation services should focus on improving mobility, advocacy to reduce stigmatization and peer support networks also need to be strengthened. Although the literature has highlighted that interventions should go beyond medical care, it does not show the correlation between uptake of inclusive development services and the quality of life of spina bifida children, which this study has explored.

## Methods

This study was carried out at Organised Useful Rehabilitation Service (OURS) in Ruharo Mission Hospital and in communities of southwestern Uganda between June 2018 and June 2019. The study participants were children with spina bifida who started receiving treatment from October 2008 to October, 2018 (0-10years old), their parents and Health care professionals. OURS is a community-based rehabilitation program (CBR) and is a specialized department of Ruharo Mission Hospital in Mbarara district. The hospital offers specialized services to children with spina bifida that is medical, therapeutic and social rehabilitation services at the center and in communities. General medical and eye treatment services are also offered at Ruharo Mission Hospital (Asasira and Ahimbisibwe, 2018). Currently it is the only facility which is currently providing Spina bifida and Hydrocephalus Interdisciplinary Program (SHIP) services in Southwestern Uganda.

The study considered a sample size of 110 respondents. These include 50 children with Spina bifida, 50 parents of children with Spina bifida and 10 health care professional working with Spina bifida service programs. Systematic sampling techniques was used to obtain the required sample from the sampling frame of available statistics of children with spina bifida enrolled on interdisciplinary care at OURS in the last ten years.

**Data Collection and analysis.** The study employed mixed methods and qualitative and quantitative data was collected. Assessment tools was used as an interaction data collation method from children with spina bifida, interview guide and questionnaire were used to collect data from parents and health care professionals. Secondary data was collected from documentary records which include OURS spina bifida program reports, OURS clients/patients' files, previous case studies, photo catalogues and previous studies. The qualitative data collected through interviews was transcribed, processed using thematic content analysis to provide complementary explanation of to the findings from the assessment of children.

**Ethical Considerations.** The study was approved by Mbarara University of Science and Technology, Faculty of Interdisciplinary studies and OURS Program management. The researchers worked with OURS' program child rights focal person since the study involved minors. According to child protection policy, 'any one working with minors must have adult care taker to assent. This policy close was followed and all parents assent for their children's participation.

## Results

Categories of descriptive data of demographic characteristics of participants are presented in three sections below as entitled; demographic characteristics of children with Spina bifida', demographic characteristics of parents of children with Spina bifida, and characteristics of health care professionals.

**Table1: Social demographic characteristics of children with Spina bifida**

Variable	Frequency	Percentage
<b>Age of the child (years)</b>		
0-2	16	32.0
2-4	11	22.0
4-6	7	14.0
6-8	3	6.0
8-10	13	26.0
<b>Gender of the child</b>		
Female/F	22	44.0
Male/M	28	56.0

*Source: Field data (April, 2019): Assessments of children with spina bifida during the study*

A total of 50 children with Spina bifida were assessed. Table 1, Shows that 32% of Children with Spina bifida who participated in this study were aged 0-2 years, 22% were aged 2-4 years, 14% were aged 4-6 years, 6% were aged 6-8 years and 26% were aged 8-10 years. This indicates that majority of respondents (54 %) sampled were younger below 4 years old followed by 26% who were 8-10 years old. This shows that there were few children operated and enrolled on interdisciplinary program for the period between 4 to 8 years ago compared to the period of 0 to 4 years ago and 8 to 10 years ago. On the other hand, it also indicated that most of the children with Spina bifida operated 8 and 10 years ago were surviving compared to children operated between 4 and 8 years ago. The results also show that majority of the respondents were males constituting 56% of total respondents while female respondents were 44% of total respondents. This indicates that there are more male clients with Spina bifida enrolled on interdisciplinary care services than females.

**Table2: Social demographic characteristics of parents of children with Spina bifida**

Variable	Frequency	Percent
<b>Parents Age (years)</b>		
≤20	1	2.0
21-30	22	44.0
31-40	12	24.0
41-50	10	20.0
51≥	5	10.0
<b>Parents Gender</b>		
F	33	66.0
M	17	34.0
<b>Parents Marital status</b>		
Married	37	74.0
Single	2	4.0
Separated	7	14.0
Widow	4	8.0
<b>Parents Education level</b>		
None	1	2.0
Primary	24	48.0
Secondary	19	38.0
Tertiary	6	12.0
<b>Parents Occupation</b>		
Peasant	30	60.0
Civil servant/NGOs	3	6.0
Business	15	30.0
Others	2	4.0

*Source: Field data (April, 2019)*

The majority of the respondents were in age bracket of 21-30 years constituted 44% of the total respondents, followed by 31-40 year (24%), 41-50 years (20%), 51 years and above (10%) while only one

respondent was below 20 years of age. This could indicate that child with Spina bifida were born across all child bearing age mothers.

From the results 66% of the total respondents were females while 34% were males. This shows that there are more female caretakers of children with Spina bifida than males. This is related to what was mentioned by most parents who participated in interviews that most men were neglecting the roles of taking care of Spina bifida children to women.

The marital status of parents who participated in this study, 74% of the respondents were married, 14% had separated, 8% were widows/widowers while 4% were single parents. Indicating that majority of parents of children with Spina bifida was in marriage. However, the percentage of parents who had separated was higher than that of the general population of 5.6% (UBOS, 2016) and this has some relationship with results of qualitative data where some mothers reported to have been divorced by their husbands for producing a child with Spina bifida.

On formal education perspective, the study found out that 48% of the parents of children with Spina bifida had attained primary level education, 38% were of secondary level, 12% had qualification from higher institution of learning and 2% had not attained any formal education. The education levels above may not necessarily be isolated for parents of Spina bifida children but reflects general education level in the community under this study (UBOS Census report, 2016). This means that children with Spina bifida were born across parents of all education levels.

The study further found out that 60% of the respondents live a peasantry life, 30% are engaged in their own businesses, and 6% are employed either by government or Non-governmental organizations while 4% are engaged in informal work. This shows that majority of parents of children with Spina bifida are in a peasantry class and may find it challenging to afford providing adequate care for their children with spina bifida.

*"The subsidized cost of surgery of children with Spina bifida at CURE Hospital is nine hundred fifty thousand shillings (950,000). This is so much subsidized because of vulnerability of the target beneficiaries otherwise, the cost of treatment in other private health facilities goes up to four million shillings. This cost is too high for majority of caregivers of children with Spina bifida who belong to the peasantry class" (Social worker, CURE Hospital during a clinic at OURS Ruharo, April 2019)*

### **Table 3: Characteristics of health care professionals who participated in this study**

Serial No	Respondents specialization	Age bracket	Sex	Number of years working in Spina bifida related area
1	Nurse	21-30	F	2-4
2	Nurse	21-30	F	2-4
3	Occupational Therapist	31-40	M	4-6
4	Physio Therapist	21-30	M	2-4
5	Physio Therapist	21-30	M	2-4
6	Social worker	31-40	F	8-10
7	Medical Orthopedic Officer	31-40	M	Above 10
8	Medical Officer/Doctor	31-40	F	4-6
9	Neurology Surgeon	41-50	M	Above 10
10	Spina bifida program Administrator	31-40	M	6-8

*Source: Field data (April, 2019)*

Table 3 above shows that a total of 10 professionals who participated in this study. Majority of the respondents were male, constituting 60 % of total respondents while female respondents were 40% of total respondents. Respondents in the 21-30 years age bracket were 40% and respondents in the 31-40 years age bracket were 50% of the total population, respondents in 41-50 years age bracket were 10% and there were no respondents in the above 50 years category. This could indicate that more of respondents who were selected were of young generation. However, all professionals who participated had worked with Spina bifida children and programs for at least four years and above. This demonstrates that the selected professionals had extensive experience on the availability and uptake of interdisciplinary care and inclusive development services by children with Spina bifida in the region.

*“Treatment of Children with Spina bifida needs specialized professionals, with well-equipped neurological departments and rehabilitation centers. However, these are still limited in the developing world. In Uganda Children with Spina bifida from all over the country have to travel to CURE Hospital in Eastern Uganda for specialized services or have to wait for limited services at Mbarara regional referral hospital and Mulago National referral Hospital where the Neurology department staffing level is below 40%. Specialized rehabilitation services are only available in few donor-funded centers, and OURS is currently the only established center in the Southwestern region” (Health worker from Mbarara regional Hospital Neurology department during assessment of children with Spina bifida at OURS, April 2019).*

## **Availability and uptake of Inclusive development services in South Western Uganda**

This study explored the significance of availability and uptake of inclusive development services by children with Spina bifida. We take close study on inclusive development under two perspectives; interdisciplinary care services provided by specialized Spina bifida centers and inclusive development services at the community level. Then we examined factors which influence their uptake to improve the quality of life of children with Spina bifida.

From 2010 to 2019, OURS program has enrolled 498 children with spina bifida on interdisciplinary care (these are children who have had surgery and are still supported by the program to maximize their development and quality of life). OURS provides comprehensive interdisciplinary care to children with Spina bifida. This requires a multidisciplinary team of Neurology surgeon, pediatric doctor, Physio and Occupational therapist, nurses, social worker and orthopedics. Currently OURS has a team of 6 staff member who are rehabilitation specialists that deal directly with provision of Spina bifida services. The doctors and the neuro surgeons positions are not filled at OURS. Therefore, OURS does not have enough human resource with specialized skills to offer surgery to such children. Through a collaboration, staff from Ruharo Mission, Mbarara regional hospitals, and CURE Hospital offer a helping hand.

Some children have been lost in care, others died and available records showed that 32 children have died in the last four years (OURS Client files, 2019). However, some children that OURS did not account for because they had not turned up for review services and they were hardly traced on the address that was given during the assessment.

### **Interdisciplinary care services offered by specialized centers**

#### **Surgical Interventions.**

Throughout southwestern Uganda specialized services for instance; surgery, continence management, and long-term rehabilitation are offered by OURS-Ruharo Mission Hospital, Mbarara Regional Referral Hospital, both located in the central district of Mbarara. For parents who can afford have to travel to CURE Children's hospital in Eastern Uganda for the same services they can access them from Mbarara, although with a limitation that they have to wait until a team from CURE hospital comes to supplement on the low number of staff in Mbarara.

*"Children with Spina bifida were referred to CURE Hospital before 2010 for surgery. Following collaboration between CURE hospitals, OURS and Mbarara regional referral hospital, for the last 8 years, services have been developed in the region and by the end of 2018, over 90% of surgeries done were being conducted from OURS-Ruharo Mission Hospital and Mbarara regional referral hospital. Long term services which include intermittent catheterization, bowel washout, physio and occupational therapy, orthopedic services, access to assistive aids and follow up services are only available at OURS in the whole region" (Health worker in-charge of pre and post-operative care of children with Spina bifida at 'OURS', April 2019).*

*"I moved from one hospital to another without help after producing a child with Spina bifida until when I met another mother who referred me to OURS and I was re referred to CURE Hospital for surgery" (Mother of a 10 years old child with Spina bifida from Kabale district, April 2019)*

### **Neurology Clinics.**

Clinics for assessment and review of people with neurological disorders are available at two centers in the whole region; Mbarara regional Hospital and CURE clinic at OURS-Ruharo Mission Hospital. Physicians explained that during the clinics, children are assessed by the specialists for the surgery, functional and development outcomes. They are also checked for hydrocephalus since majority of post Meningocele closure (MMC) develop hydrocephalus. Children with Spina bifida are given regular review appointments for neurology clinic at Mbarara regional referral hospital, or at a monthly clinic conducted by CURE Hospital at OURS.

*"We review approximately 60 children with Spina bifida every month at Mbarara regional referral hospital through our weekly clinics" (Health worker from Mbarara regional hospital neurology department during surgery of children with Spina bifida at OURS-Ruharo mission hospital, April 2019).*

*"Parents tend to observe review appointments given by the health workers during the first year after surgery but later they may come at their convenience or when the child is sick" (Data Management Officer- OURS, April 2019).*

*"I miss clinic appointments because it is very expensive for me to travel to Mbarara every two months. So, when my child is not sick, I may not come". (Mother of a 4 years old child from Rukungiri district, April 2019)*

In this study, we found out that most children with spina bifida quality of life had improved during post-operative period. The children that observed review appointments were doing well compared to those that missed some appointments.

### **Continence management**

According to health care professionals, children with Spina bifida have the problem of incontinence of urine and stool due to damage of nerves in the spinal cord. The objective of continence management is to protect children with Spina bifida from renal system complications and improve social continence. Incontinence is managed using clean intermittent catheterization (CIC) and bowel wash out management techniques.

*"All children with Spina bifida are initiated on intermittent catheterization during the first review after surgery. This service is free at OURS and continence management supplies are supplied by donors" (Health worker in charge of continence management-OURS, April 2019)*

*"I regularly come to OURS to collect continence materials for my child because the practice has saved me of bad smell. My child can now paly with others". (Mother to a 5 years Spina bifida child in Mbarara, April 2019)*

Our study documents such success stories in continence management of children with spina bifida. This has not only reduced the bad smell but increased their level of acceptability and social inclusion in communities and amongst their peers. With adequate staffing, the services would be much better and children with spina bifida will easily integrate with their peers and stigmatization among parents and children would reduce.

### **Rehabilitation services.**

All parents who participated in this study receive rehabilitation services from OURS Rehabilitation center. They were happy that rehabilitation services at OURS were friendly and free of charge. Some parents reported to be experiencing difficulties in attending to all review appointments due to transport related costs, challenges of transporting older children with Spina bifida regularly, family misunderstandings and other social responsibilities. Rehabilitation specialists at OURS observed that over the years, children who undergo long term rehabilitation program have improved health outcomes compared to those who fail to continue after surgery.

*"I regularly visit OURS for exercises and catheterization for that reason, my child quality of life has been improving for the last eight years". (Mother to a 9 years old girl with Spina bifida in Mbarara, April 2019).*

*"I would like to go for rehabilitation but my child is too heavy to carry. It is also expensive travelling by taxi. So, I have to wait for health workers from OURS to come to our community for outreach clinic and I take him" (A parent of 8 years old child with Spina bifida who was visited at home in Kanungu district, April 2019).*

*"Most of children with Spina bifida who have consistently followed rehabilitation program are doing well. However, children who do not come for rehabilitation are usually found in communities with secondary disabilities like contractures, pressure sores and urinary tract infections. We have lost some of them as a result of secondary complications" (A rehabilitation worker at OURS, April 2019).*

### **Inclusive development services at community level**

#### **Health care services in communities**

Respondents were able to explain the general health care system as follows. At community level there are health center II's which are available in a few communities. These are followed by health center III's at the sub county level and health center IV'S at county or district level. Some districts have both health center IV's and district general Hospitals. Different levels of health care services are offered at each level (Asasira and Ahimbisibwe, 2018). Referrals are made to district and regional hospitals in case the conditions cannot be handled at the health center levels.

Health workers further elaborate on services which are provided in health centers as follows. General health checkup, child immunization program, HIV/AIDs services, maternal and child health services, minor surgeries, treatment of common infections like malaria, respiratory tract infections, and sexual transmitted diseases. These services are available for all people.

*“Children with Spina bifida should not be travelling long distances to Mbarara for treatment of infections like malaria fever because these services are available in their communities. But sometimes health workers in health centers refer them because they just fear the word Spina bifida or Hydrocephalus” (A health worker at Ruharo Mission Hospital during review of sick children at OURS department, April 2019).*

All parents expressed concerns that children with Spina bifida are taken as special cases which cannot be managed at lower level health centers. They reported to have experienced difficulties while trying to access general health services for children with Spina bifida in health centers in their communities. There were mixed feelings with some parents reporting an improvement in some health centers where sensitization has been conducted while others saying health workers are completely not giving them due attention.

*“My child is usually treated at the health center and when a child is born with Spina bifida, health workers call me to give pieces of advice to the parents” (Mother of a 7-year-old Spina bifida child from Ntungamo district, April 2019).*

*“Every time I take my child to the health center for treatment, health workers say her condition can only be managed where she was operated from. It is expensive for me to travel to Mbarara or CURE Hospital all the time” (Mother to a 4-year-old girl with Spina bifida from Ntungamo district, April 2019).*

### **Access to Education facilities.**

Although the government of Uganda has implemented Universal Primary Education (UPE), access to education by children with Spina bifida remains a major challenge. Out of 50 children who participated in this study, at least 23 were of school going age and only 5 of them were able to access schools. This means that 82.3% of school going aged children with Spina bifida are not accessing education. Difficulty in accessing schools was the most significant factor expressed by children with Spina bifida, their parents and professionals during interviews. Most parents also reported that Children with Spina bifida are not accepted in schools because of challenges of mobility limitations and incontinence which causes stigmatization.

*“I have tried over 4 schools and my child has been denied admission into these schools. Teachers say they cannot manage her conditions. Now I have given up” (Father to an 8-year-old boy with Spina bifida, April 2019).*

*“I spend the whole day at home alone because all my brothers and sisters go to school. My parents tell me schools are far they cannot manage to take me every day” (a 10-year-old girl with Spina bifida found at home in Bushenyi district, April 2019).*

*“Children with Spina bifida who are not in school are left indoors, parents go to work while their siblings go to school. We find them at home with secondary disorders like pressure sores, urinary tract infections and deformities during home visits” (A CBR worker at OURS, April 2019).*

### **Community development programs.**

Majority of parents (84%) were aware of availability of the following development programs in their communities; National Agricultural Advisory Services (NAADS), Special grant for women, and Operations Wealth Creation (OWC). Only 22% of the respondents had information about availability of Special grants for PWDs and Community Driven Development (CDD) projects for groups. Two out of eight Spina bifida parents’ associations where the respondents are members reported to have received community driven development grants from their respective district community development offices. More than a half of respondents (54.47%) belonged to other development groups in their communities. This clearly indicated that parents of children with Spina bifida were free to join development groups like any other community member and benefit from existing government programs.

On the other hand, parents reported to be finding difficulty participating and benefiting from specific programs which are designed for empowerment of marginalized groups. Most empowerment programs are targeting women, PWDs, orphans and people with HIV/AIDs, leaving out children with spina bifida as vulnerable group in the community.

*“Associations for people with Spina bifida are not considered to benefit from PWDs grants. The target beneficiaries are adults with disabilities. Children with disabilities who cannot advocate by themselves are left out” (Leader of Spina bifida association-Southwestern Uganda, April 2019).*

*“We are not supported by CSOs like other vulnerable people in our communities. Having a child with Spina bifida puts us at a disadvantage compared to other members of the community. We need extra resources to take care of such a child. Some of us we were chased away from work because we are ever in hospitals” (Mother to a 5-year-old Spina bifida boy, April 2019).*

### **Spina bifida Associations.**

A total of 41 (82%) of the parents of children with Spina bifida were members of Spina bifida associations. Spina bifida and Hydrocephalus Associations are community-based organizations which are initiated by parents of children with Spina bifida with the aim of having a forum through which challenges they face can be addressed. According to the respondents the associations are paramount in promoting awareness about Spina bifida and advocating for the rights of people with Spina bifida in their communities. They also collaborate with other partners to have services available for children with disabilities in their communities.

*"I enjoy coming to a parents' association because they bring specialists who teach us about the conditions of our children and how to care for them" (Father to a 3-year-old Spina bifida child, April 2019).*

*"When I gave birth to a child with Spina bifida, people told me that such children do not grow. However, I have been strengthened by other parents during association activities and meetings" (Mother to a 2-year-old Spina bifida attending parents training in Rukungiri group, April 2019).*

*"Our associations are registered with local governments and some local leaders have started participating in our activities to promote the rights of people with Spina bifida" (Parents leader of Isingiro district, April 2019).*

## **Factors influencing the uptake of interdisciplinary and community inclusive development services by children with Spina bifida**

### **Distance to service centers.**

Distance was identified as major factor which affects uptake of interdisciplinary care services by children with Spina bifida. Specialized interdisciplinary care service providers are located in the central district of Mbarara yet children with Spina bifida are spread all over the region. Therefore, parents must travel from their home districts to access neurology surgery services, attend regularly neurology review clinics, continence management services and rehabilitation programs. Both parents and professionals concurred that parents from districts far from Mbarara miss review appointments while others turn up only when their children are sick.

*"Most parents give excuse of lack of transport needed for regular travels. Children who are lost in follow up are found in communities with manageable secondary disorders during home visits". (A health worker at OURS, April 2019).*

*"I need seventy thousand shillings (70,000 Uganda shillings) every two months if I am to attend review appointments. My husband has given up, so I have to look for money myself yet I have many children to take care of" (Mother of a 6-year-old child with Spina bifida from Kanungu district, April 2019).*

*"Unless OURS comes to our community for outreach, I cannot go for services in Mbarara because I do not have money for transport" (Parent of a 4-year-old child with Spina bifida Mitoma district, April 2019).*

### **Limited skilled human resource.**

Both professionals and parents reported challenges of shortage of personnel and capacity in health facilities to provide services to children with Spina bifida. This remains a challenge for both specialized hospitals, health centers and community service providers.

*"Inexperienced health workers in specialized hospitals hardly guide parents especially on the need for long term care services. So, children with Spina bifida are discharged and are never enrolled on services like continence management and rehabilitation program. By the time we meet them, they have already*

*developed secondary disorders which would have been avoided” (A health worker during CURE Clinic at OURS, April 2019).*

*“Health workers in communities lack information and means to deliver basic health care services to children with Spina bifida. They refer all the children to us or send them back home” (A rehabilitation specialist at OURS, April 2019).*

*“I have been going to regional referral hospital for five times now without help. Doctors are telling me to come back next week, next week, because the specialist is not around. The head of my child is growing too big and she is vomiting all the time” (A mother of a 10 months old child with Spina bifida at OURS, April 2019).*

### **Limitation of Collaboration between service providers.**

The study established that services for children with Spina bifida are limited to specialized centers and institutions. However, no single institution had the capacity to provide services to meet the needs for improved quality of life of children with Spina bifida. Therefore, combined efforts through partnerships and collaboration were identified as key factors which can positively affect access and uptake of inclusive development services by children with Spina bifida.

*At OURS we provide, comprehensive rehabilitation services to children with Spina bifida. However, surgeries and specialized investigations are done through collaboration and partnership with Mbarara regional referral hospital and CURE Hospital” (A health worker in charge of rehabilitation of children with Spina bifida at OURS, April 2019).*

### **Negative attitudes**

All parents reported to have experienced discrimination either directly to the child with Spina bifida or to themselves. Children with Spina bifida are not treated like other children both by their families and by service providers. Parents of children of school going age reported to have been denied vacancies in public schools. Some of the children who were in school either paid extra fees or were known personally to school owners. During interviews some parent was quoted reporting that *“I have four children and one with disability”* this could indicate that a child with disability comes second after others.

*“I have difficulty taking care of this child because when I produced him, the father divorced me saying that in their family, they do not produce children with disabilities” (Mother of a 5-year-old child with Spina bifida in Mbarara, April 2019).*

### **Limited resources.**

Professionals reported limited in funding in the health sector and institutions that provide services to people with disabilities. There is lack of specialized facilities in public health facilities as a contributing factor to inaccessibility of services by children with Spina bifida. Parents of children with Spina bifida

have to pay for some services like brain CT scan, orthopedic aids and other essential supplies in hospitals because such services are either cost shared or privately run. Some of the poor parents who cannot manage the expenses cannot get these services.

*“At the regional referral hospital where surgeries are conducted, there is no specific ward for admission of post-operative neurological cases. Children with Spina bifida are usually admitted in overcrowded pediatric ward with other children having a range of infections and thus prolongs their recovery” (A health worker from Mbarara regional hospital during the clinic at OURS-Ruharo mission hospital, April 2019).*

*“We cannot conduct follow up of all children with Spina bifida as required. OURS receives children with disabilities from all over south and western Uganda yet we have a limited number of staff” (A rehabilitation worker at OURS, April 2019).*

### **Accessibility policies.**

Both parents and professionals reported that most of the public structures cannot meet accessibility standards for children with special needs for example spina bifida. The four schools which were visited during this study to assess children with Spina bifida had inaccessible classrooms and toilets for children using assistive aids. Similar accessibility challenges are experienced in homes of children with Spina bifida, health institutions, and workplaces among other public places.

*“I have to leave my wheel chair in class and crawl on the ground whenever I want to go out of class or else I sit in the class for the whole day because my wheelchair cannot move over the door steps” (A 9-year-old child with Spina bifida in Mbarara, April 2019).*

*“I am not in school because my parents told me that teachers said they only admit children who can walk” (A 6-year-old child with Spina bifida during home visit, April 2019).*

### **Donor dependence**

One other significant factor that was raised by professionals is dependence on external funding for service provision to children with Spina bifida. Currently the services for Spina bifida are dependent on donor funding which is limited and project specific. Where the donation cannot reach to provide the necessary service, there is much limitation thus leaving a big gap in extending quality and desired services to children with spina bifida.

*“For the last four months, we have had a stock out of supplies like oxybutynin medication in Uganda because it is only accessed through donation. Other supplies like appropriate assistive aids, orthotics, remain very expensive for parents and can only be accessed through donations” (A health worker in charge of rehabilitation of children with Spina bifida at OURS, April 2019).*

## **Discussion**

Our findings indicated that having information about Spina bifida and long-term care is prudent in utilizing available services at different levels. Parents who were aware of the need for long-term care and consistently followed long-term treatment program had their children scoring highly on the Quality of life (QOL) scale. Professionals had the same concern that some health workers discharged children with Spina bifida after surgery without informing parents on the need for long-term care because they lacked that information. Such children developed secondary complications like severe hydrocephalus, upper renal system deterioration and disuse deformities which would have been prevented or treated with good outcomes. Therefore, lack of information on spina bifida management by health workers contributed significantly to failure in provision of inclusive services. The findings are concurred with earlier studies on factors affecting survival of infants with myelomeningocele in Southeastern Uganda (Sims-Williams et al., 2017).

This study found out that the survival and the quality of life of children with Spina bifida is affected by the contextual situations of families of children with Spina bifida for example the parent's capacity to utilize available long-term interdisciplinary care. The study shows that even with successful operation Myelomeningocele closure (MMC), children with Spina bifida are likely to suffer and die of renal system deterioration, pressure sores, disuse deformities, malnutrition and other infections. These disorders can be managed both at the community level by health workers, family members and specialists in specialized centers. Therefore, if parents lack capacity due to their social, cultural and economic situation, the quality of life of their children is likely to be compromised. The findings agree with earlier studies by (Warf, Wright, et al. 2011) which found out that surgery only opens the door towards life, implication for starting of other interdisciplinary long-term services. And other studies on interdisciplinary care for children with spina bifida in East, Southern Africa (Mertens & Bannink, 2012).

One other important factor indicated in this study was the implication of observing the rights of children with Spina bifida. Children whose rights to basic needs, participation and inclusion were observed scored high on the quality of life scale during assessment process. However, children whose rights were denied had increased difficulties in health, development and functional domains. The issue of child rights abuse was of a concern at all levels from families to community neighborhood, service providers, policy makers and implementers. Despite the laws and policies on child protection, inclusion and not discrimination being in place, they remain less implemented. For example, our findings indicate that 82.3% of school going age children with spina bifida were unable to attend schools. This situation depicts the picture in the earlier studies on the state of children with disabilities in Uganda which shows that only 9% of children with disabilities (CWDs) are able to attend schools (UNICEF, 2014).

Although the available literature shows the level of accessibility to inclusive development services by children with disabilities in different communities, it does not clearly demonstrate how this impact on the quality of life, especially on children with Spina bifida. This study established that growing children with Spina bifida who were not enrolled for community inclusive development services like inclusive education scored poorly on the quality of life magnitude, irrespective of the level of uptake of specialized medical services. This gives a new perspective that connects the relationship between uptake of specialized

medical services and other community based inclusive development services, on the quality of life of children with Spina bifida.

### **Study limitations.**

This study had the following limitations. First, lack of social functioning and environmental participation measurement tools in Uganda's context. Despite having translated ICF-QOL measurement tool to fit the socio-cultural context, different research assistants interpreted it differently while doing assessment of quality of life of children with Spina bifida. Secondly, children with intellectual and language difficulties were challenging to handle during assessment procedures and much of the information collected depended on responses from parents and professionals' views.

## **Conclusions**

Based on the research findings a conclusion can be drawn covering 3 main issues. Quality of life of children with Spina bifida in south western Uganda; factors affecting availability and uptake of Inclusive development services by children with Spina bifida; and the relationship between availability and uptake of inclusive development services on the quality of life of children with Spina bifida.

The study established that for over a decade, specialized centres have tried to provide treatment and long-term care to children with Spina bifida in the region which has resulted into children with Spina bifida growing from infancy to childhood and youthful age. This is indicated by progressive increase in the number of children receiving interdisciplinary care services and the numbers of children who have been maintained on long term care for the last 10 years (OURS-SHIP Report 2018).

Over the years, there has been improvement in establishing services for Spina bifida in the region. The study findings indicate that children with spina bifida from the region used to be referred to CURE Hospital in Eastern Uganda for neurology surgery until 2013 when the services were initiated by Mbarara regional referral hospital in collaboration with OURS-Ruharo Mission Hospital. Parents still incur costs of investigations like brain CT scan, blood tests and access to other consumables which remain expensive. Currently over 90% of the new spina bifida children identified are operated with in Mbarara. The service is still undergoing development and is supported by CURE Children's Hospital. Long term interdisciplinary care which include physio and occupational therapy, continence management, orthopedic services, adaptive rehabilitation and follow ups services in the community are available at one facility-OURS in the entire region. There were mixed views on the uptake of available interdisciplinary care services with some of the respondents reporting to have experienced challenges related to regular travels for services which are only available at specialized centers in Mbarara; Mbarara Regional Referral Hospital and OURS-Ruharo Mission Hospital Mbarara.

On the other hand, availability and uptake of inclusive development in the community remain a major challenge to children with spina bifida and their families. Majority of parents and children with Spina bifida reported unequal treatment and unequal opportunities in enjoyment of available social services in

the community. From the findings, we noted that denial of access to education services among children with spina bifida was a human right abuse of the highest order. Most parents reported that their children have been rejected in a number of public schools due to their physical presentation (big-heads), incontinence and limited mobility. On overall, the issue of physical accessibility by children with disabilities in the region is pretty dismal: although laws have been enacted to provide for accessibility, little effort has been made to enforce them.

Regarding the relationship between availability and uptake of interdisciplinary care services and inclusive development services, our findings indicate a strong linear relationship between the quality of life of children with spina bifida and uptake of interdisciplinary care services and a moderate strong relationship with uptake of community inclusive development services.

Despite all what has been reported in this paper, we argue that children with disabilities have “the same needs as other children”. In fact, they have the same rights as others, among these, are the right to life and to the opportunities that flow from good health care, nutrition and education, right to express their views and participate in community settings. This still awaits realization with in the region and entire country-Uganda.

## **Recommendations**

Based on the findings, the study recommended the following,

### **Health care and rehabilitation services.**

While many people are aware of, and would like to use, specialized medical services and rehabilitation experts, they are often out of reach for children with disabilities like spina bifida. Services are either too expensive or too far away, while those which are closer by might not be relevant to these children. This study recommends that the government should recruit and place more medical rehabilitation specialists at district-level health facilities to enable children with disabilities to access long term care efficiently. Physiotherapists, occupational therapists, counselors, orthopedics, vision therapists, speech therapists, should work together as a team and be with easy access to those who need to use their services. Also, neurology departments in regional referral hospitals also need to be equipped with additional necessary resources that can match the increasing needs of patients with neurological disorders. Academic institutions need to develop a range of programs specializing in neurology and other spina bifida related treatment so that the health human resource in neurology is enhanced.

### **Sensitization and advocacy for the equal rights.**

Although the study revealed that public awareness about disability issues has increased, and there is evidence of improvements in attitudes and practices among family members and communities. Uganda has many enabling policies and laws aimed at protecting the interests of children and creating equal opportunities for people with disabilities. The study findings indicated that the wider community continues to exhibit some negative attitudes and practices which work against social integration. A

substantial number of children with disabilities are discriminated in families and when accessing social services in public places. We recommend that performance indicators for disability service delivery are included in local government performance assessments. This will urge local governments and central government departments to pay more attention to the rights of children with disabilities in general. Sensitization should also include advocacy for promotion of preventive measures since more children with spina bifida continue to be born in the region.

### **Community based rehabilitation program.**

Findings from this study indicated that children with Spina bifida from hard to reach area in the region and districts far away from Mbarara scored low on the quality of life magnitude. This was due to failure to observe review appointments for interdisciplinary care services after surgery leading to development of secondary disorders. Therefore, the study recommends development of comprehensive CBR program where long-term interdisciplinary care services can be taken closer children in their communities e.g home care rehabilitation, outreach clinics, networking and partnership.

We recommend training in neuro surgeons to deal with Spina bifida operations and health care services for post-operation of children with spina bifida. Higher institution of learning should get interested in training surgeons, nutritionists, orthopedics among other with specialization in caring for spina bifida children. There is a need to engage academic institution through research collaboration to deeply investigate and invent appropriate technology-responsive mechanisms to improve adherence to reviews after surgery, more neuro surgeon and doctors should be trained to provide specialized care to spina bifida children. Such public-private partnerships will lead to improved outcomes in the quality of life, ease provision of CBR and cost-friendly services to children with spina bifida. The government of Uganda should devote funds to support spina bifida treatment through the Ministry of Health (MoH).

## **List Of Abbreviations**

MUST- Mbarara University of Science and Technology

OURS- Organized Useful Rehabilitation Services

MoH- Ministry of Health

CBR- Community Based Rehabilitation

IDS- Inclusive Development Services

CIC- Clean Intermittent Catheterization

QOL- Quality of Life

## **Declarations**

## **Ethical Approval and Consent to participate**

Ethical approval was sought to from participants to be part of this study. MUST, OURS, allowed this study to be conducted.

## **Consent for publication**

Not applicable.

## **Availability of supporting data**

Supporting data is available on special request and has been presented in the current publication.

## **Competing interests**

The authors declare no competing interests.

## **Funding**

No funding was received to conduct this study.

## **Authors' contributions**

Ganshanga wrote the concept, collected data, wrote the first draft of the manuscript. Asasira guided on idea conceptualization, designed data tools, analyzed data, wrote the manuscript and revised it further for publication, identified the journal where to publish the paper.

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