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Clean intermittent catheterization in Tanzania: Understanding the practices and perceptions of caregivers of children with spina bifida post-training.

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B.A. Dartmouth College, 2012

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An abstract of
A thesis submitted to the
Faculty of the Rollins School of Public Health at Emory University
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By Christopher Valleau

Background: Continence management training programs to teach clean intermittent catheterization and other skills to caregivers of children with spina bifida were first implemented in Tanzania nearly two decades ago. These trainings are incredibly important as many of these children suffer from pediatric neurogenic bladder, a bladder dysfunction caused by nervous system damage, which can lead to skin breakdown from urine leakage, kidney failure, and early mortality. However, no formal evaluation of these trainings has been carried out in Tanzania, and the literature examining acceptability and efficacy in similar low-resource settings is limited.

Methods and Findings: We conducted a cross-sectional survey to collect data on the experiences of caregivers of children with spina bifida attending continence management trainings in Mwanza and Dar es Salaam, Tanzania, as well as data on implementation of learned practices post-training. A questionnaire was administered to forty-seven participants by phone. Exploratory analysis and descriptive statistics were carried out with the goals of describing caregivers' experiences at trainings, describing continence management practices post-training, and identifying program successes and challenges. Identified successes included an early start to CIC for many children, positive outcomes in fecal continence management, relatively high adherence to CIC given the challenges faced, and highly motivated parents. Perhaps the biggest barrier to program success was the low uptake of intravesical oxybutynin as part of CIC practice (< 5%), likely due in part to a lack of hands-on training using this medicine. Other barriers included lack of follow-up, low rates of self-catheterization, lack of mobility support, and difficult economic conditions faced by families.

Conclusion: Continence management training programs were found to be acceptable and feasible in this setting. However, given that fewer than 5% of participants were found to use intravesical oxybutynin, a critical component of a proper CIC regimen, it is difficult to say that these trainings have been fully successful. That said, that nearly half of participants reported regularly catheterizing their children despite numerous barriers is promising. While the continence management training programs in Tanzania have limitations in their current form, numerous successes are present and major improvements are possible with reasonable changes.

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TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION

Introduction and Rationale

This study was conceptualized and initiated by the leadership of Child-Help International (CHI), a Belgium-based not-for-profit organization that seeks to improve the lives of children living with neural tube defects (NTDs) globally through work with partner organizations. One of CHI's major activities is the implementation and improvement of training programs on continent management through the use of clean intermittent catheterization (CIC) for parents and caregivers of children living with spina bifida. This study was designed to assess the efficacy of past CIC training programs offered by CHI's partners in Tanzania and to understand successes and barriers faced by children and caregivers in this realm. This study was carried out in coordination with the Center for Spina Bifida Prevention at Emory University.

Problem Statement

The authors could find no in-depth evaluation of a continence management training program in a low-resource setting examining practices, successes, and barriers from the perspective of caregivers of children with spina bifida in the existing literature. Additionally, no study of any kind evaluating continence management/CIC training programs in Tanzania, which have been ongoing for 18 years, could be found in the literature. **In addition to the need for a formal evaluation of continence management training programs in Tanzania, there is a paucity of studies evaluating these programs across all low- and middle- income countries (LMICs).**

Purpose Statement

The purpose of this study is to evaluate the efficacy of continence management/CIC training programs in Tanzania through understanding the training and post-training experiences of caregivers of children with spina bifida who attended them.

Research Objectives

The goal of this study was to evaluate the efficacy of continence management trainings in Dar es Salaam and Mwanza, Tanzania and to identify successes in and barriers to proper continence management by caregivers post-training. The research objectives of this study, to be achieved through the collection and analysis of questionnaire data, were as follows:

- Describe caregivers' experiences attending CIC trainings in Tanzania
- Describe the continence management practices of caregivers and children with spina bifida post-training
- Identify successes in continence management training programs and post-training practice in this setting
- Identify barriers and challenges to caregivers' adoption of proper continence management practices in this setting

Significance Statement

This research will assist Child-Help International in understanding the efficacy of continence training programs being implemented by their local partners in Tanzania. It will help them to identify areas of success that can be built upon as well as obstacles that will need to be overcome to ensure that the children they are seeking to help receive the best

care possible. This research will also help to close the gap in the existing literature around continence management training programs in LMICs.

CHAPTER 2: BACKGROUND

Profile of Spina Bifida in Tanzania

Spina bifida is a type of neural tube defect (NTD), birth defects of the brain and spine that occur when the neural tube does not form and close properly during early pregnancy. Along with anencephaly, spina bifida is among the most common NTDs.[1] Spina bifida can range in severity depending on the location and size of the neural tube opening and is known to cause mortality and disability. A common complication is neurogenic bladder, a bladder condition related to neurological damage which causes urine to be retained in the kidneys and which, untreated, can lead to kidney failure and early mortality.[1] NTDs, spina bifida included, have been shown to be preventable with adequate folic acid intake in the perinatal period,[2] which can be achieved through supplementation or consumption of fortified foods. Both methods of folic acid consumption are safe for mothers and babies.[1] Folic acid fortification, typically of wheat and maize flour, has been shown to be an extremely cost-effective intervention. In the U.S., every dollar spent on mandatory folic acid flour fortification since its implementation in 1997-1998 has been shown to avert nearly $150 in medical expenses.[3]

Approximately 300,000 babies are born yearly with spina bifida and other NTDs, leading to nearly 90,000 deaths and 8.6 million disability-affected life years (DALYs).[4] Spina bifida rates are systematically undercounted, even in the global North, because stillbirths and induced abortions may not be included in official counts.[1] Even so, in countries where folic acid flour fortification has been mandated, rates of spina bifida have

dropped significantly.[1] In the U.S., where fortified food products are widely consumed, the prevalence of NTDs is only 3.2 per 10,000 live births.[4]

In countries without widespread availability or consumption of fortified staple grains or prenatal supplements, NTD rates are much higher. Tanzania experiences a spina bifida prevalence of 26 per 10,000 live births, one of the highest in the world.[1] In 2011, Tanzania adopted the Tanzania Food, Drugs and Cosmetic (Food Fortification) Regulations, which mandated fortification of wheat and maize flour beginning in 2013.[5] While only half of wheat flour and a third of maize flour that passes through industrial mills is fortified,[6] this initiative has been shown to have a beneficial effect. A study of the urban women of reproductive age in Dar es Salaam demonstrated a reduction in the prevalence of folic acid deficiency from 27% to 5% in this population, attributed to the Tanzanian government's mandated fortification of wheat flour.[7] Despite this achievement, in Tanzania, a country of about 50 million, two-thirds of the population live in rural areas,[8] and 85-90% of the land is used by subsistence farmers.[9] Because of this, only about 20% of maize, the country's major staple food, passes through industrial mills, meaning that the vast majority of the flour used by the average Tanzanian is unfortified.[6] While small-mill fortification technologies show great promise, barriers to large-scale implementation remain and widespread coverage has not been achieved.[10] A nationally representative study carried out in 2015 found that less than 20% of wheat flour and 3% of maize flour were adequately fortified.[11]

A second factor contributing to high spina bifida prevalence in Tanzania is an extremely low rate of prenatal diagnosis and induced abortions. In high-income countries,

prenatal diagnosis of spina bifida is often followed by fetal surgery or induced abortion.[12,13] In Tanzania, prenatal diagnosis remains rare, fetal surgical options are limited,[14] and it is extremely difficult to get a legal abortion, which are only permitted by law only in order to save the life of the mother.[15]

A study of mothers of infants with hydrocephalus and spina bifida admitted to the Muhimbili Orthopaedic Institute (MOI) in Dar es Salaam between 2013-14 sought to understand barriers to NTD prevention in the realms of culture, diet, education, medicine, and geography. Results showed that 85% of participants subsisted on a maize-based diet. Only 3% took folic acid supplementation, despite nearly two-thirds stating they wished to have another baby, suggesting a lack of knowledge of the causal relationship between folic acid and NTDs even among mothers who had birthed and were caring for children with spina bifida and hydrocephalus. Three-quarters of these mothers had not progressed beyond primary school, and many had not attended school at all,[16] a similar education profile to that of the female population nationally.[8] A study of women of reproductive age in the Morogoro region of Tanzania in 2017 found that awareness of folic acid or folic acid fortification was associated with higher folic acid intake, but awareness of these factors was low (<8%).[17] Given that wide-scale folic acid fortification of flour has not been achieved, preterm diagnosis followed by induced abortion is nearly unheard of, and that knowledge and adoption of folic acid supplementation is rare, it is clear that the average Tanzanian woman does not yet have the knowledge or resources necessary to prevent spina bifida and other NTDs.

Treatment for Spina Bifida and its Complications

In high-income countries, a child born with spina bifida will quickly undergo surgery to protect the spinal cord from further damage and infection, which greatly reduces risks of mortality and long-term disability.[13] In Tanzania, though 98% of women have reported receiving prenatal care for their most recent pregnancy, fewer than two-thirds of babies are delivered in health-care facilities, which can impede spina bifida diagnosis.[8] Additionally, medical personnel may not be adequately trained to recognize spina bifida and other NTDs at birth, particularly if the presentation is less obvious. While spina bifida surgery is available at regional hospitals, in Tanzania as in other low-income countries delayed diagnosis as well as cultural and socioeconomic factors can mean that these critical surgeries can happen later than is needed or may not happen at all.[14,18]

One frequent complication experienced by children with spina bifida is pediatric neurogenic bladder, caused by damage to the spinal cord. Untreated or undertreated, pediatric neurogenic bladder can cause urinary incontinence and can result in hydronephrosis and kidney failure, which occurs in 50% of untreated patients by the age of 5 and is a common cause of death in these patients.[19] In addition to the health risks of pediatric neurogenic bladder, the social impact of urinary incontinence and fecal incontinence, which is also a common problem but generally simpler to manage, on children with spina bifida and their caregivers is significant.[20] In a qualitative assessment of the experiences of children with spina bifida and their caregivers, continence emerged as the central theme, permeating every part of the children's lives. Good continence management was found to be key in reducing isolation, to combating feelings of stigma, and to maximizing children's independence and ability to socialize with their peers.[21]

Treatment of urinary incontinence involves the practice of clean intermittent catheterization (CIC), whereby a sterile urinary catheter is inserted into the urinary tract in order to aid in emptying the bladder.[20] This practice is frequently accompanied by the use of anticholinergic therapy, typically intravesical oxybutynin, which increases renal pressure and helps the bladder to empty fully during catheterization. While the long-term health effects of oxybutynin are still being assessed, it is generally thought to be safe. Use of oxybutynin with spina bifida patients beginning at two-months of age has been associated with healthy kidney development.[22] CIC paired with oxybutynin therapy is recommended for use in low-income countries such as Tanzania, given that it is safe, cost-effective, and relatively simple to teach to patients and caregivers. It is highly recommended that bladder diagnosis and management begin early in a child's life to prevent renal damage and failure.[19] To prevent kidney damage and keep children dry between sessions, CIC is typically performed every 4-6 hours. Children with spina bifida who are not prevented from doing so by severe disability frequently learn to self-catheterize around the age of six years old.[23] In the US, two-thirds of children with spina bifida achieve "social continence," meaning that urine leakage between catheterizations is minimal and implying that the kidneys are protected from damage, through CIC and anticholinergic therapy alone.[24] In addition to catheterization, caregivers who undergo CIC training are frequently taught to manage other conditions associated with spina bifida, namely skin breakdown from urine leakage, management of urinary tract infections (UTIs), fecal continence management through enemas, and management of mobility issues.[24,25]

For several decades, efforts to teach CIC to parents and caregivers of children with spina bifida have been undertaken in several low-income settings. Results have shown that

barriers to successful implementation of these programs are numerous and complex, but that CIC programs in low- and middle-income countries (LMICs) can be efficacious with thoughtful execution and persistence. Formal assessments of these programs in the literature, however, are few. A 2004 study of 194 infants and children living with spina bifida in Kenya assessed the effectiveness of a CIC training program for caregivers over an 18-month period. While 9% of the patients unfortunately died due to disease-related complications, approximately half of those enrolled in the study achieved continence through catheterization alone or catheterization with anticholinergic therapy, successfully reducing renal damage and other complications. A fifth of those enrolled were spontaneously continent and did not require CIC. The study authors recommended that for full success, economic barriers for caregivers must be better addressed, education opportunities for caregivers increased, and communication between medical staff and caregivers be prioritized.[26] A study of post-operation outcomes among children with spina bifida in Uganda found that, similar to the study in Kenya, 83% required continence management. While CIC adherence was low among study participants, results showed that the practice was associated with greater urinary continence.[27] A study of stress factors among caregivers of children with spina bifida in Uganda found that over 80% practiced CIC, which caregivers saw as useful and necessary for their child's health and well-being. Caregivers also reported, however, that CIC was a time-consuming practice which was hard or impossible to undertake outside of the home, posing particular challenges with regards to school attendance.[28] Results from a study in Malaysia echoed these findings.[29]

In Tanzania, efforts to train caregivers, usually mothers, of children with spina bifida have been underway for nearly 18 years, with most trainings taking place in cities with

large referral hospitals that caregivers and children visit for surgeries and follow-ups, namely Mwanza, Arusha, Haydom, and Dar es Salaam on the Tanzanian mainland, and Stone Town on the semi-autonomous island of Zanzibar. Organizations that have led these trainings include the Association for Spina Bifida and Hydrocephalus in Tanzania (ASBAHT), Child-Help Tanzania (CHT), and several large hospitals including CCBRT Arusha and Haydom Lutheran Hospital. ASBAHT is an organization founded and led by parents and caregivers of children living with NTDs. CHT, formerly Friends of Children with Cancer Tanzania, is closely associated with and funded by Child-Help International (CHI). CHI's global mission is to prevent NTDs, raise awareness about these conditions, and help children with spina bifida and hydrocephalus in low-income countries to live healthy, productive lives.[30] CHT provides trainings based in Dar es Salaam and Mwanza. Despite the long history of these trainings in Tanzania, no formal evaluation of their efficacy has been carried out. There is a need to understand the impacts of these programs on the health and wellbeing of the children with spina bifida they serve.

CHAPTER 3: METHODS

We conducted a cross-sectional survey to collect data on the experiences of caregivers of children with spina bifida attending continence management trainings and implementing learned practices post-training.

Study Participants

Participants in this study were caregivers of children with Spina Bifida in Tanzania who had attended one or more Clean Intermittent Catheterization (CIC) trainings held by ASBAHT, Child-Help Tanzania, and/or Friends of Children with Cancer. These individuals were identified from databases of past training participants provided by training organizations and contacted by phone. Of the list of 87 contacts provided to study staff, 74 were found to have up to date, active cell phone numbers. Seven individuals indicated that their child had passed away since the training. Of the remainder, 52 were successfully contacted and informed about the study opportunity. Of those contacted, 47 completed the questionnaire, a 90% response rate.

Data Collection

Data Collection Tool

Data collection was prospective and consisted of a questionnaire (see **Appendix A**) administered by phone to participants, typically in a single, 1-hour interview. The questionnaire tool was prepared in English, translated into Swahili, and back translated by a separate translator to ensure translation accuracy and meaning retention.

The questionnaire was developed based on preliminary results from an unpublished qualitative study of a subset of the study population living in the greater Dar es Salaam,

Tanzania area. The purpose of the questionnaire was to quantify findings identified in the qualitative study and to describe characteristics of the respondents' children/grandchildren living with spina bifida, their training experiences, their socioeconomic situations, and various measures of CIC success.

The anonymous questionnaire consisted of six sections. The first section collected basic information about the child with spina bifida including age, gender, mobility level and mobility management. The second aimed to determine how many trainings a caregiver had attended and with which organizations, assess the caregiver's satisfaction with these trainings, and determine whether the caregiver had the opportunity to practice CIC with their child under supervision. The third section assessed the caregiver's experience with fecal continence management. The fourth section, the longest, sought to understand the caregiver's experience with urinary continence management, and included questions about catheterization, oxybutynin, UTIs, diaper use, and skin breakdown from urine leakage. The fifth section asked questions about schooling and, where applicable, about how the child's continence management routine differed on school days versus non-school days. The sixth and final section asked questions about care-seeking and the family's economic status. Nearly all survey questions were close ended.

Methods of Data Collection

A medically trained Tanzanian interviewer familiar with CIC practice and local terminology administered the questionnaires by phone. During each phone call, the study was explained to participants, who were then screened for eligibility. Participants were asked whether they had previously attended at least one continence management training

in Dar es Salaam or Mwanza, and whether they were still the caregiver for a child with spina bifida. Informed consent was obtained verbally using the following method: Participants were first read a verbal consent form. They were told about the purpose of the study, possible benefits and harm to themselves, and made aware of their rights. They were given the contact information of each study staff member and researcher, as well as the contact information of the Emory IRB. The were asked if they had any questions, and any questions or needed clarifications were addressed. They were told that the phone call would not be recorded but that their answers would be written down by the survey administrator. Then, they were asked whether they agreed to participate in the study. Their names were not recorded as the protocol required anonymity of these subjects. Rather, the survey administrator conducting the informed consent discussion signed and dated the verbal consent form. Once verbal consent had been obtained, each participant answered a series of 53 questions over the course of an approximately one-hour interview. After the data was collected, the interviewer debriefed each participant, again making sure they understood the purpose of the study and how the data was to be used, confirmed that they had recorded the specified contact information, and answered any remaining questions.

Data Entry and Analysis

Data from the paper questionnaires completed by the interviewers was entered into and stored in a password-protected Microsoft Access database. Personally identifiable information from the explanatory responses was omitted. Data was entered twice and compared to ensure accuracy, and then the paper questionnaires were destroyed.

Responses from questions requiring short explanations were translated from Swahili to English independently by two translators and the translations were compared for meaning.

Data were analyzed with R (version 4.0.5) using the RStudio software (version 1.2.5033). Variables representing each survey question were examined for completeness and distribution. Frequencies were used to describe categorical variables. Median and range values were used to describe continuous and ordinal variables. Data representing Likert-type scales were visualized using the Likert function from the HH statistical package.[31]

Ethics Approval

The study protocol was approved by the Emory University Institutional Review Board (IRB, IRB#00001711). All participants provided verbal informed consent at the time of enrollment.

CHAPTER 4: RESULTS

In total, 52 participants were contacted and asked to respond to the questionnaire. Of these, three indicated they did not have the time to respond to the questions and two indicated they did not wish to participate for other reasons. In total, forty-seven participants answered the questionnaire. Of these, 35 were mothers, seven were fathers, and five were grandmothers of a child with spina bifida. Age data for the participants were not collected.

Household Characteristics

Study participants were from households clustered in two regions, two-fifths in the greater Dar es Salaam area and three-fifths in the greater Mwanza area. The median weekly household income was 3,500 Tanzanian shillings, or about $1.50 U.S. dollars (see **Table 1**).

Table 1: Summary of clean intermittent catheterization survey results

Characteristic	Number[1]	n
Household Location		47
Greater Dar es Salaam	19 (40%)	
Greater Mwanza	28 (60%)	
Child has access to an assistive device at home or school	20 (43%)	45
Child needs one or more assistive devices he/she does not have access to	28 (64%)	44
Weekly household income (Tanzanian shillings)	3,500 (0 - 30,000)	44
Number of CIC trainings attended	2 (1 - 5)	47
Child was catheterized under supervision during training		46
Yes, one time	13 (28%)	
Yes, more than one time	29 (63%)	
No	4 (8.7%)	
Child had oxybutynin administered under supervision during training		46
Yes, one time	5 (11%)	
Yes, more than one time	11 (24%)	
No	30 (65%)	
Regularly performs enemas on child	30 (65%)	46
Child is regularly catheterized	21 (45%)	47
Number of times child is catheterized on a typical non-school day	3 (0 - 5)	19
Duration that child stays dry after catheterization (minutes)	35 (0 - 180)	26

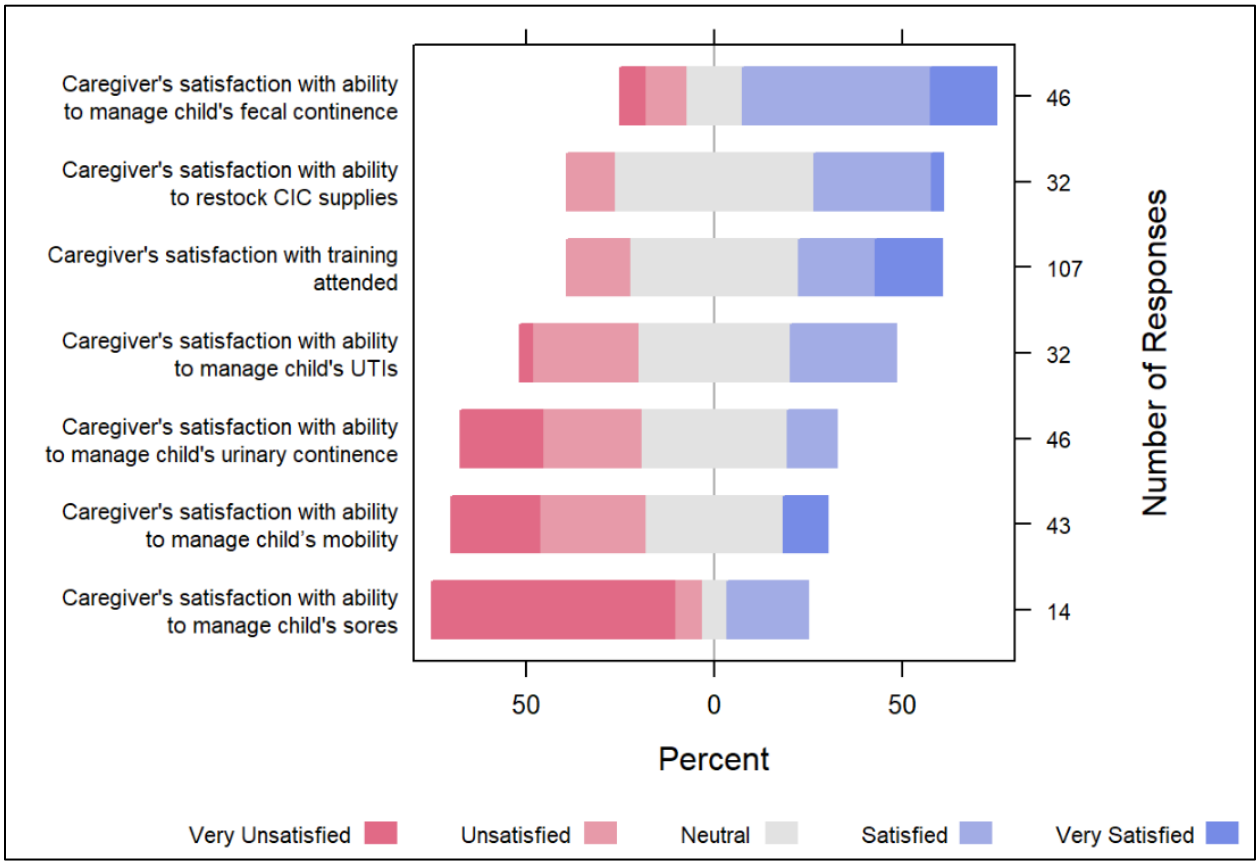
Characteristic	Number[1]	n
Caregiver has administered oxybutynin to child outside of training	2 (4.9%)	41
Child has experienced skin breakdown/sores from urine leakage in past 3 months	15 (35%)	43
Child has been diagnosed with a UTI in past 3 months	24 (53%)	45
Caregiver practicing CIC experienced problems restocking supplies in past 6 months		21
Yes	7 (33%)	
No	14 (67%)	
Child attends school		47
Yes, full time	19 (40%)	
Yes, part time	3 (6.4%)	
No	7 (15%)	
Not yet (too young)	18 (38%)	
Travel time to referral hospital (hours)	3 (0 - 10)	43
Time since most recent appointment at referral hospital (months)	6 (0 - 72)	41

[1]Categorical data are reported as n (%). Numerical data are reported as median (%).

Characteristics of Children

Two-thirds of the participants' children were male (31 [66%]). Less than a quarter (10 [22%]) were able to walk without assistance. Less than half of the children had access to an assistive device at home or school. Those that did mainly had access to wheelchairs (11 [24%]) and/or braces/special shoes (7 [16%]). Two-thirds of participants indicated that their child required one or more assistive devices that they did not have access to, including wheelchairs (14 [32%]), braces/special shoes (12 [27%]), and walkers (10 [23%]). Half (22 [51%]) of participants expressed being unsatisfied or very unsatisfied with their ability to manage their child's mobility (see **Figure 1**).

Figure 1: Caregiver satisfaction with issues related to child's continence care



Training Experiences

On average, caregivers attended two (1 – 5) continence management trainings, typically spaced a year or two apart. Across the trainings they attended, most caregivers had the chance to catheterize their child under the supervision of a trainer or another parent or caregiver. Only four (less than 10%) said they had never had this experience. Few caregivers, however, had the experience of administering intravesical oxybutynin under supervision, with two-thirds stating they had never had this experience. Recalling their training experiences, on average participants were "neutral" to "unsatisfied" with the quality of the trainings they attended (see **Figure 1**).

Continence Practice

Fecal Continence Management

The practice of enemas for fecal continence management was common, with two-thirds of caregivers reporting they regularly performed enemas on the children. Most caregivers reported positive results regarding fecal continence management, with 23 (50%) reporting they were "satisfied" and 8 (17%) reporting they were "very satisfied" with their ability to manage their child's fecal continence (see **Figure 1**).

Urinary Continence Management

Catheterization

The practice of clean intermittent catheterization was also common, with about half of caregivers reporting that their child was regularly catheterized. Of these, CIC was performed an average of three times daily on typical days when the child was not in school. Among those caregivers who did not regularly practice CIC, 13 (52%) reported never having done so, but 12 (48%) reported having previously practiced CIC but said they had stopped doing so. Reasons for never starting CIC included:

- They were told the child needed to be circumcised (5 [38%])
- They were told the child was still too young (2 [15%])
- There is a problem with the child's urethra and surgery is needed first (2 [15%])
- The caregiver saw blood in the urine when they tried it (1 [8%])
- The caregiver got sick (1 [8%])
- CIC hurt the child (1 [8%])
- The child has some sensation and is able to urinate without CIC (1 [7%])

Among those who had previously practiced regular CIC, reasons for stopping included:

- Lack of time (5 [42%])
- The child does not usually stay with the caregiver (2 [17%])
- CIC hurt the child (2 [17%])
- The caregiver began seeing blood in the urine (1 [8%])
- CIC did not prevent the child from being wet (1 [8%])
- The child has severe sores on the genitalia due to constant wetness which prevent it (1 [8%])

Among those who practiced CIC, the median reported time the child stayed dry after catheterization was approximately a half hour. Lubricant use in catheterization fell squarely along gender lines, with all caregivers of male children using lubricant during CIC, and none of the caregivers of female children doing so. Sunflower oil was the exclusive lubricant used. Only 5 (14%) of the children were able to self-catheterize, and all were male. The average age of those children able to self-catheterize was 12 (6 - 18) years old versus 8 (1 - 21) years old for those who could not. Among those who regularly catheterized their children, two (10%) reported that another adult regularly performed CIC on the child as well.

Overall, compared with fecal continence, caregivers were less satisfied with their ability to manage their child's urinary continence. On average, they reported that they were "neutral" to "unsatisfied" about their ability to do so (see **Figure 1**).

Oxybutynin use

Of the 47 caregivers interviewed, only two reported having ever administered intravesical oxybutynin to their child outside of a training environment. Both caregivers reported that they regularly administered oxybutynin to their child as part of their CIC

practice, though one told the interviewer that restocking it was a major difficulty. Caregivers' reasons for not doing so included the following:

- "I don't know" (17 [49%])
- Did not believe it was safe (5 [14%])
- Did not know how to use it properly (4 [11%])
- Did not believe they could trust in a regular supply (3 [8.6%])

Diaper use

In addition to CIC practice, 36 (95%) of caregivers reported daily use of disposable diapers with the children. On average, children who wore disposable diapers used 4 (2 - 8) on a typical day. Caregivers said that, were the cost of diapers not an issue, they would use 8 (2 - 12) per day.

Health issues related to urinary continence

Of those caregivers who regularly practiced CIC, seven (33%) reported seeing blood in their child's urine at least one time during the past month. All seven of these children were male, as were the two children whose caregivers discontinued or never started regular CIC practice due to witnessing blood in their urine.

About one-third of the caregivers reported that their child had suffered from sores/skin breakdown due to urine leakage in the past three months. Of these, two-thirds (10 [67%]) stated that these sores were "a very big problem."

About half of caregivers reported that their child had been diagnosed with a UTI in the past three months. Of these, 16 (89%) said that a urine test had been used to diagnose

the most recent UTI. Eleven (46%) said that the most recent UTI had been accompanied by a fever. Caregivers were split about their ability to manage their child's UTIs (see **Figure 1**).

Issues restocking continence management supplies

Of the caregivers regularly practicing CIC, one-third reported having had issues restocking CIC supplies in the past six months. On average, caregivers indicated that their ability to restock CIC supplies was "neutral" to "satisfactory" (see **Figure 1**).

School

Among the children, about half attended school full- or part-time and about a third reported as too young to attend (see **Table 1**). Reasons for children not attending school or attending part-time included:

- Urinary continence issues prevented the child from attending/fully attending (4 [44%])
- Transport to school posed a major problem (3 [33%])
- Fecal continence issues prevented the child from attending/fully attending (2 [22%])
- Mental deficiency (1 [11%])

Most (15 [68%]) of the children attended public school, with the rest attending a private institution. At school, only 3 (14%) of the children had an adult who was able to help them manage their continence. To get to school, most children were either carried on someone's back (8 [42%]) or pushed in a wheelchair (5 [26%]), with the remainder taking public or private transportation, walking, or boarding at school. While collecting standardized data regarding distance travelled to school proved difficult, many participants

reported that it was a kilometer away or less, though others reported having to carry their child for over an hour each way. Of the 15 children who practiced CIC and attended school, nearly all (13 [87%]) of the caregivers said that while at school, the child was catheterized less frequently than at home.

Care-seeking

In case they encountered a problem managing their child's condition, 39 (87%) said they would go to the closest referral hospital. When asked about barriers to accessing care at the referral hospital, caregivers reported the following issues:

- High travel cost (16 [38%])
- High cost of hospital fees (13 [31%])
- Difficult to find time to go (8 [19%])
- Difficulty scheduling an appointment (4 [9.5%])
- No perceived benefit (1 [2.4%])

The median time since the child's most recent visit to a referral hospital was six months. The median travel time to the closest referral hospital was three hours (see **Table 1**).

CHAPTER 5: DISCUSSION

This study aimed to understand and quantify the experiences of caregivers of children with spina bifida attending CIC trainings and implementing continent management practices post-training. Through administering a questionnaire to caregivers and analyzing the results, we were able to identify successes in and challenges to proper continence management uptake and adherence. Facilitators to program success included an early start to CIC for many children, positive outcomes in fecal continence management, relatively high adherence to CIC given the challenges faced, and highly motivated parents. Barriers to program success included low uptake of intravesical oxybutynin as part of CIC practice, likely due in part to a lack of hands-on training using this medicine, an apparent lack of follow-up by the training organizations, low rates of self-catheterization, lack of mobility support, and difficult economic conditions faced by families.

The average caregiver surveyed had attended two trainings, though some attended as many as five. While the criteria and processes for attending subsequent trainings were not made clear to the authors, most participants waited a year or two in between trainings. Subtracting children's current ages from the year of first training, we found that the median age at first training was 3 (<1 – 17) years old. According to the literature, an early start to CIC is important for acceptance by the child and for optimal health outcomes,[19,24] with initiation recommended in the first year of life,[22,32] meaning that this is a possible area for improvement by the organizations implementing these trainings. Referral systems should be examined to ensure that children are beginning as early as possible. That some children started when they were less than one year old is promising, and that success should be built upon. Another success of the training program was that all but four (8.5%) caregivers

had the experience of catheterizing their child under the supervision of a trainer and/or another caregiver at least one time during the trainings they attended. For two of these children, the caregivers reported that there were anatomical issues that prevented them from being catheterized. Concerningly, one of these individuals had attended their first training in 2018 but the child still had not undergone the needed surgery three years later, suggesting that ongoing follow-up and support had not been received. The other two individuals who had not catheterized their child under supervision were told they had to wait until the child was circumcised, a contraindication not found in the literature (three others reported not engaging in regular CIC practice for this reason). Alarmingly, even though nearly all caregivers had the experience of catheterizing their child at a training, only one-third used intravesical oxybutynin with their child during these hands-on sessions, something that is critical to CIC success in most cases.[19,32] This is a major gap that critically undermines the potential for success in this program. Intravesical oxybutynin increases the pressure in a child's kidneys, allowing for greater drainage of urine during catheterization, leaving the child dry longer and protecting their kidneys from damage.[20,22,32]

Post-training, two-thirds of caregivers reported they had adopted the practice of performing enemas on their child for fecal continence management. This appeared to be an area for success, as two-thirds of caregivers reported being "satisfied" or "very satisfied" with their fecal continence management abilities. Less success seems to have been found with urinary continence, which half of caregivers said they were "unsatisfied" or "very unsatisfied" with their ability to manage. Less than half of caregivers (21 [45%]) reported that they regularly performed CIC on their child, a remarkably high number given that

without the use of oxybutynin, most children stayed dry for less than an hour post-catheterization. Of the 47 participants, only two reported having ever used oxybutynin with their child. Again, this is a major area of concern. Without the aid of oxybutynin, the bladder is not able to fully drain during CIC, exposing children's kidneys to damage and increasing the risk of UTIs,[22,24] which more than half of children had suffered from in the three months prior to the questionnaire. Also, without oxybutynin use, children are more likely to leak between CIC sessions, exposing them to possible skin breakdown. A third of children had suffered from these lesions in the past three months.

Examining the reasons why caregivers never adopted a regular CIC practice post-training, or had adopted it but later stopped, it is noteworthy that most of the problems did not appear insurmountable. These organizations should reevaluate whether circumcision is a necessary criterion for CIC practice and follow-up with caregivers accordingly. Similarly, if the child was deemed too young for regular CIC, follow-up mechanisms should be put in place so that when they come of age, the caregiver is reminded and, if possible, retrained. One caregiver who was trained in 2018 and was told their child was too young for CIC still had not adopted the practice three years later. Issues such as blood in the urine, pain during catheterization, sores on the genitalia, or even a problem with the urethra requiring surgical intervention should not mean that CIC practice is abandoned or never adopted. Rather, these issues should prompt further investigation, support, and follow-up on the part of any organization seeking to help these children.

The reasons that caregivers did not use oxybutynin with their children were less clear, as half said they "don't know" why they don't use it. That only a third received hands-

on experience with oxybutynin at the trainings they attended was likely a major factor. That some caregivers indicated they did not believe it was safe should be of concern to the organizations hosting these trainings. The lack of trust in a regular supply should be noted as well. While only one-third of participants engaged in regular CIC practice had experienced supply issues in the past six months, given that CIC is critical to physiological and psychosocial wellbeing for children with neurogenic bladder,[19,27,32] this number would ideally be zero.

Another barrier to consistent CIC practice was school. About half (21 [46%]) of the children in the sample attended school part- or full-time. Only three (14%) of these children however had an adult at school who was able to help them manage their continence. Additionally, in the entire sample, only five children were able to self-catheterize. In combination, this meant that of the 15 children who practiced CIC and attended school, nearly all (13 [87%]) were reported to have less frequent CIC practice at school than at home. Some caregivers reported that this lack of ability to manage urinary continence prevented the child from attending school. If a child is old enough and has the mental faculties to attend school, they should be able, given the proper training, to self-catheterize.[23] In order to increase children's independence and reduce barriers to continence management at school, organizations implementing CIC trainings should emphasize the importance of self-catheterization and prioritize the acquisition of this skill. Literature on interventions for children and adolescents with asthma and type-1 diabetes in other African countries suggests that self-management is possible and is linked to better outcomes in similar settings.[33,34] Literature from high-resources settings indicates that children with spina bifida as young as six can realistically engage in this practice,[23] and the

five children reportedly able to do so in this study further suggest that this practice is feasible and acceptable.

The economic conditions of these families are also important to understand, as they affect many of the other issues assessed. Survey data showed that these caregivers' average income was approximately $1.50/week. This number is not necessarily comparable to the per capita income reported in the 2015-16 Tanzania Demographic Health Survey and Malaria Indicator Survey, approximately $800/year or $16/week,[8] as seasonal income such as from crop scales may not have been captured. Rather, it reflects how much cash a caregiver might have for day-to-day expenditures, such as diapers, medicine, or transportation. It makes clear that many of these families are quite poor, and that limited cash availability reduces caregivers' ability to provide the best care for their children. For example, the average caregiver in the sample expressed that if money was not an issue, they would use four additional diapers for their child daily than they currently use. That so many children experience problems with skin breakdown due to urine leakage is almost certainly a symptom of poverty.

Additionally, that two-thirds of children need one or more assistive devices that they don't have access to is a major barrier to good health and quality of life for these children, and it is not something that most families can easily overcome with their current income. As of 2021, at CCBRT hospital in Dar es Salaam, all-terrain wheelchairs, well-suited to the rural environments in which many participants lived, were available to low-income children for a family contribution of 65,000 TZS, or just under $30. Even this low cost, however, could be too much for families to afford. Others may not be aware that these

devices are available. While structural barriers regarding mobility will remain even for children with wheelchairs due to lack of accessible infrastructure, wheelchairs suited to rural environments can still mitigate many challenges faced. Organizations interested in helping these children should examine ways they can support them, financially and otherwise, to access needed assistive devices.

Economic conditions also came into play when examining care-seeking behavior. When asked hypothetically about facing a problem managing their child's condition, most (39 [87%]) caregivers said they would go to the closest referral hospital. Asked to identify barriers to accessing care at this hospital, 16 {38%) indicated high travel cost and 13 (31%) indicated high cost of hospital fees as issues. This should be a concern for organizations involved in helping these children: if accessing care represents a significant financial commitment, it may dissuade families from getting help early, which could potentially exacerbate health problems these children encounter.

Recommendations for Future Programming

Organizations currently offering this training in Tanzania and other low resource settings, as well as organizations seeking to expand or implement continence management training programs for parents in similar settings, should consider the following recommendations based on the results of this study. These organizations should:

1. Systematize referral mechanisms for beginning training as well as systems for ongoing follow-up post-training
2. During follow-up, assist caregivers in mitigating identified challenges to continence management uptake and adherence

3. Prioritize hands-on practice with intravesical oxybutynin during trainings and understand and address other barriers to uptake
4. Prioritize self-catheterization teaching and practice at trainings
5. Revisit evidence-based indications and contraindications for CIC training, particularly around circumcision, and train staff on guidelines to ensure clear and consistent messaging
6. Provide families with information, logistical support, and, if possible, financial assistance to address mobility challenges
7. Identify and close gaps in supply chain in order to mitigate issues faced by families restocking continence management provisions
8. Provide or connect families to economic empowerment training, ensuring that start-up capital is provided, in order to reduce financial burdens of families accessing medical care and buying needed supplies such as diapers

While following these recommendations may not fully mitigate every challenge caregivers and children face, with thoughtful implementation and prioritization of limited resources, the authors believe that continence management training programs in this and similar settings can be highly successful.

Strengths and Limitations

This study is, to the authors' knowledge, the first in-depth evaluation of a continence management training program in a low-resource setting examining practices, successes, and barriers from the perspective of caregivers of children with spina bifida.

One limitation of this study was that because data was collected by questionnaire, the complexity of the successes and challenges to proper continence management faced by the caregivers could not be fully explored. A second limitation was recall bias, as participants were asked to recall trainings attended up to six years prior. That being said,

the majority of questions focused on more recent occurrences that would be simpler and more reliable for the participants to recall. Another limitation was the lack of variation in the responses to certain questions. One planned secondary analysis, for example, was to identify characteristics associated with proper CIC uptake, particularly around oxybutynin, as anecdotal evidence had suggested that few caregivers used it. Since only two out of 47 caregivers were found to use oxybutynin, it was not possible to develop a profile of caregivers who did so. A second interest of the authors was to examine the safety of using sunflower oil rather than traditional lubricant for CIC, specifically asking the questions of whether it was associated with greater incidence of complications such as blood in the urine or UTIs. Since not a single participant used conventional lubricant, and since lubricant use was determined by the child's gender, this link could not be explored. Future research to understand the acceptability and efficacy of oxybutynin in this setting, and to evaluate the safety of using sunflower oil as a catheterization lubricant, is needed. A fourth limitation was a low number of participants, primarily due to a relatively small number of individuals who had attended trainings in these two regions, which limited the authors' ability to explore complex relationships between variables. Lastly, the cross-sectional nature of the questionnaire made it impossible to explore changing views by participants.

Implications and Conclusion

The purpose of this study was to evaluate the implementation of CIC practices following trainings for caregivers held in the greater Dar es Salaam and Mwanza areas of Tanzania. Given that less than 5% of the study participants reported using intravesical oxybutynin, a critical component of a proper CIC regimen, with their children, it is difficult to say that these trainings have been fully successful. That said, the fact that nearly half of

participants reported regularly catheterizing their children, sometimes years after attending a training, despite numerous barriers, and despite it appearing to have little positive effect on their children's urinary continence, is a reason for hope. It was made clear from the survey results that these caregivers are strongly motivated to help their children: they attend trainings with them, they carry them to school on their backs every day, and they travel, sometimes all day and at significant cost, to take them to hospital appointments. While the continence management training programs in Tanzania have major limitations in their current form, numerous successes are present, and improvements are possible with reasonable changes.

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APPENDICES

Appendix A: Questionnaire

RESPONDENT ID: _____

START TIME: _ _ : _ _ AM/PM

SECTION 1: CHILD INFORMATION

INTERVIEWER SAY: "*I would like to begin by asking you a few questions about your child who is living with spina bifida.*"

Q1. Is your child a male or a female?
   a) Male
   b) Female

Q2. How old is your child? __ __ Years

Q3. Does your child's disability prevent them from walking without assistance?
   a) Yes
   b) No
   c) Don't know

Q4. How satisfied are you with your ability to manage your child's mobility?
   a) Very unsatisfied
   b) Unsatisfied
   c) Neutral
   d) Satisfied
   e) Very Satisfied

Q5. Does your child use any of the following devices at home or school to assist with mobility? CHECK ALL THAT APPLY
   a) Wheelchair
   b) Special shoes/braces
   c) Walker
   d) Other, list: _____

Q6. Does your child need but not have access to any of the following devices to assist with mobility? CHECK ALL THAT APPLY
   a) Wheelchair
   b) Special shoes/braces
   c) Walker
   d) Other, list: _____

SECTION 2: CIC TRAINING

INTERVIEWER SAY: *"Now, I would like to ask you about your past experience attending a CIC training or trainings. Remember that your responses will remain anonymous and confidential."*

Q7. First, please list all previous CIC trainings that you have attended, your year of attendance, and your level of satisfaction with that training (very unsatisfied, unsatisfied, neutral, satisfied, very satisfied)

Q8. TRAINING ORGANIZATION OR LOCATION	Q9. YEAR OF ATTENDANCE	Q10. SATISFACTION
Q11. 1. _____	Q12. _ _ _ _	Q13. _____
Q14. 2. _____	Q15. _ _ _ _	Q16. _____
Q17. 3. _____	Q18. _ _ _ _	Q19. _____
Q20. 4. _____	Q21. _ _ _ _	Q22. _____
Q23. 5. _____	Q24. _ _ _ _	Q25. _____

Q26. During any of these trainings, did you catheterize your child with the supervision of a trainer or another parent?
a) Yes, one time
b) Yes, more than one time
c) No

Q27. During any of these trainings, did you use oxybutynin with your child with the supervision of a trainer or another parent?
a) Yes, one time
b) Yes, more than one time
c) No

Q28. Would you recommend CIC training to another parent of a child with spina bifida?
a) Yes
b) No

SECTION 3: FECAL CONTINENCE

INTERVIEWER SAY: *"Now, I would like to ask you some questions about your child's fecal continence."*

Q29. Do you regularly perform enemas on your child?
a) Yes
b) No

Q30. How satisfied are you with your ability to manage your child's fecal continence?
a) Very unsatisfied
b) Unsatisfied
c) Neutral
d) Satisfied
e) Very Satisfied

SECTION 4: URINARY CONTINENCE

INTERVIEWER SAY: *"Now, I would like to ask you some questions about your child's urinary continence."*

Q31. How satisfied are you with your ability to manage your child's urinary continence?
a) Very unsatisfied
b) Unsatisfied
c) Neutral
d) Satisfied
e) Very satisfied

Q32. Do you or someone else regularly catheterize your child?
a) Yes <- SKIP TO QUESTION 22
b) No

Q33. Did your child previously have a routine of frequent catheterizations? THEN What was the reason?
a) Yes. LIST REASON FOR STOPPING: _____ <- SKIP TO QUESTION 23
b) No. LIST REASON WHY NOT: _____ <- SKIP TO QUESTION 23

Q34. On a normal day when your child is not in school, how many times are they catheterized on average? __

Q35. When your child is catheterized, is lubricant used?
a) Yes
b) No <- SKIP TO QUESTION 19

Q36. What kind of lubricant is used during catheterization?
a) Water-based glycerin lubricant
b) Coconut oil
c) Sunflower oil
d) Other cooking oil

e) Other, list: _____

Q37. Other than yourself, is there another adult who regularly catheterizes your child?
a) Yes
b) No

Q38. Is your child able to self-catheterize?
a) Yes
b) No

Q39. In the past month, have you noticed blood in your child's urine during catheterization?
a) Yes, one time or several times
b) Yes, many times
c) No

Q40. How long does your child stay dry after catheterization on average? __ __ hours

Q41. How comfortable would you feel training another parent of a child with spina bifida on CIC practices?
a) Very uncomfortable
b) Uncomfortable
c) Neutral
d) Comfortable
e) Very Comfortable

Q42. Outside of a training, have you ever used intravesical oxybutynin with your child?
a) Yes
b) No <- SKIP TO QUESTION 27

Q43. Do you regularly use intravesical oxybutynin with your child?
a) Yes
b) No <- SKIP TO QUESTION 27

Q44. What are the reasons you use oxybutynin with your child? SELECT ALL THAT APPLY
a) You were told you should <-SKIP TO QUESTION 28
b) You want to protect your child's kidneys <-SKIP TO QUESTION 28
c) It helps keep your child dry <-SKIP TO QUESTION 28
d) It helps prevent UTIs <-SKIP TO QUESTION 28
e) Other, list: _____ <-SKIP TO QUESTION 28

Q45. What are the reasons you don't use oxybutynin with your child? SELECT ALL THAT APPLY
a) I don't know how to use it
b) I don't have a reliable supply
c) I do not believe it is safe to use
d) I don't know
e) Other, list: _____

Q46. Does your child wear diapers?

a) Yes
b) No

Q47. On an average day when your child is not at school, how many diapers do they use per day? __ __ diapers

Q48. I understand that diapers are expensive, and it is not always possible to buy them. If you always had as many diapers as you needed, how many diapers would your child use per day? __ __ diapers

Q49. In the past 6 months, have you experienced any problems restocking continence supplies such as catheters or oxybutynin?

a) Yes, one time
b) Yes, more than one time
c) No

Q50. How satisfied are you with your ability to restock continence supplies such as catheters or oxybutynin?

a) Very unsatisfied
b) Unsatisfied
c) Neutral
d) Satisfied
e) Very satisfied

Q51. In the past 3 months, has your child had skin breakdown/sores due to urine leakage?

a) Yes
b) No <- SKIP TO QUESTION 36

Q52. How big of a problem are these sores for you and your child?

a) A very big problem
b) A fairly big problem
c) A small problem
d) Not a problem at all

Q53. How satisfied are you with your ability to treat these sores?

a) Very unsatisfied
b) Unsatisfied
c) Neutral
d) Satisfied
e) Very satisfied

Q54. In the past 3 months, did your child have a UTI?

a) Yes
b) No <- SKIP TO QUESTION 38

Q55. For the most recent UTI, what was used to diagnose it? CHECK ALL THAT APPLY

a) A urine test
b) Visual inspection (Cloudy urine)

c) Symptom: fever
d) Symptom: pain or discomfort
e) Other: _____

Q56. How big of a problem are UTIs for your child?
a) A very big problem
b) A fairly big problem
c) A small problem
d) Not a problem at all

Q57. How satisfied are you with your ability to treat these UTIs?
a) Very unsatisfied
b) Unsatisfied
c) Neutral
d) Satisfied
e) Very satisfied

SECTION 5: SCHOOL

INTERVIEWER SAY: *"Now, I would like to ask you some questions about your child's schooling."*

Q58. Does your child attend school?
a) Yes, full time <- SKIP TO QUESTION 42
b) Yes, part time. Explain: _____ <- SKIP TO QUESTION 42
c) No
d) Not yet (too young) <- SKIP TO QUESTION 47

Q59. What are the reasons for your child not attending school? SELECT ALL THAT APPLY
a) Transportation problems <-SKIP TO QUESTION 47
b) School leadership refused them because of their condition <-SKIP TO QUESTION 47
c) If they went to school, they could not manage their urinary continence <-SKIP TO QUESTION 47
d) If they went to school, they could not manage their fecal continence <-SKIP TO QUESTION 47
e) Other, list: _____ <-SKIP TO QUESTION 47

Q60. What kind of school does your child attend?
a) Public
b) Private

Q61. Is there someone at your child's school who can help manage their continence?
a) Yes
b) No

Q62. How far away is the school from your home? __ __ kilometers

Q63. How does your child normally travel to and from school?

a) They are a boarding student
b) They walk
c) They are carried on somebody's back
d) Somebody pushes them in a wheelchair
e) They push themselves in a wheelchair
f) They take private transportation (e.g. car or motorcycle)
g) They take public transportation (bus)
h) Other, list: _____

Q64. Is your child's continence routine different on school days compared to non-school days? CHECK ALL THAT APPLY

a) Catheterized less frequently
b) Oxybutynin is used less
c) Other: _____

SECTION 5: FINAL QUESTIONS

INTERVIEWER SAY: *"We have come to the final section. I have just a few more questions for you before we are done."*

Q65. If you were to experience a problem with your child's condition, who would you contact? CHECK ALL THAT APPLY

a) Another parent of a child with spina bifida
b) A representative of a spina bifida organization (e.g. ASBAHT, Child-Help Tanzania)
c) A local clinic or pharmacy
d) The regional referral hospital
e) Other, list: _____

Q66. Which is the closest referral hospital where your child can be treated for their condition?

a) MOI, Dar es Salaam
b) Bugando Hospital, Mwanza
c) Haydom Hospital, Manyara
d) ALMC Arusha
e) Other, list: _____

Q67. How long ago was your child's most recent appointment at this hospital? __ __ Months

Q68. If you were to travel to this hospital, how long would it take you? __ __ Hours

Q69. Do you experience any of the following barriers accessing care at this hospital? PLEASE CHECK ALL THAT APPLY

a) Difficulty scheduling an appointment
b) Cost of travel is high

c) Cost of hospital visit is high
d) No perceived benefit
e) Difficult to find time to go
f) Other barrier: _____

Q70. If your child experienced a major health problem, how confident do you feel about your ability to get help for them?

a) Very confident that I could not get help
b) Somewhat confident that I could not get help
c) Neutral
d) Confident that I could get help
e) Very confident that I could get help

Q71. In an average week, what is your household income? __ __ __ __ __ __ Shillings

INTERVIEWER SAY: *"That is the end of my questions. Thank you for your participation."*

END TIME: _ _ : _ _ AM/PM