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Qualitative evaluation of clean intermittent catheterization training programs for parents of children with spina bifida in Dar es Salaam, Tanzania.

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B.S.N. University of Wisconsin Madison, 2013

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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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Qualitative evaluation of clean intermittent catheterization training programs for parents of children with spina bifida in Dar es Salaam, Tanzania

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Background: As neurosurgical outcomes for children with spina bifida improve in Tanzania and other low and middle income countries (LMICs), there is a need to better understand management of common childhood complications, particularly regarding continence and kidney function. Kidney disease is a leading killer of these children, but risks can be reduced with proper continence management and the use of clean intermittent catheterization. Continence management training programs have existed in Tanzania for two decades, but no formal evaluations of these programs have been conducted in this setting.

Methods and Findings: We conducted a qualitative study of 17 parents of children with spina bifida in Dar es Salaam, Tanzania to understand their experiences at continence management trainings and facilitators and barriers to success implementing CIC following the trainings. In-depth interviews were conducted with parents who had attended one or more continence management trainings. Participants were recruited from local support groups for parents of children with spina bifida. The analysis revealed strengths of the trainings, including teaching methods and the formation of peer support networks, and weaknesses, including myths and misinformation and critical missing components. A lack of systems, structural barriers, and socioeconomic challenges were the primary barriers to successful implementation post-training. Support networks, highly motivated parents, and program acceptance all facilitated success at implementation post-training.

Conclusion: Acknowledging the numerous barriers to successful program implementation in settings with limited resources, there are many notable successes. Many of the challenges identified are possible to overcome with relatively low cost and reasonable measures. With practical changes, the continence management training programs evaluated can improve their efficacy in changing the lives of children with spina bifida in Tanzania and similar settings. More research is needed after initial implementation of the primary recommendations to re-evaluate efficacy post-improvement.

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CHAPTER 1: INTRODUCTION

Introduction and Rationale

Child-Help Tanzania is an organization that is working to improve quality of life for children with neural tube defects in Tanzania. The Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT) is a support group that provides services to the same population. One of the programs offered by both organizations is continence management trainings for caregivers of children with spina bifida in Dar es Salaam, Tanzania. This work is important as many children with spina bifida suffer from pediatric neurogenic bladder, a condition which can lead to kidney damage and eventually kidney failure, a major cause of mortality in this population. Child-Help International, a not-for-profit organization based in Belgium which partners with these two organizations, initiated this study with the purpose of evaluating the strengths and limitations of continent management trainings in Tanzania so that changes can be made to the programs to allow for more successful outcomes.

Problem Statement

Pediatric neurogenic bladder, usually the result of a neural tube defect (NTD), can cause renal failure and urinary incontinence if left untreated. In Tanzania, efforts to train caregivers of children with spina bifida on continence management have been underway for 18 years, but program staff report anecdotally that many children still suffer from renal damage, skin wounds, social incontinence, and early mortality. However, a formal evaluation of the efficacy of the continence management training programs has not been conducted. Without such a study, it is not possible to know whether these programs are working and to what extent.

Purpose Statement

This project sought to evaluate continence management training programs for caregivers of children living with spina bifida in Dar es Salaam, Tanzania, to understand barriers to successful continence management implementation, and to find potential pathways for program improvement.

Research Objectives

The goal of this study was to evaluate strengths and barriers to the continence management training programs underway in Dar es Salaam, Tanzania to allow for effective program improvements. The aims of the project were to:

1. Conduct qualitative interviews with affected families to understand experiences at trainings and barriers and facilitators to successful implementation of continence management after trainings
2. Provide recommendations to implementing organizations based on identified strengths and barriers to success, allowing for program improvement.

Significance Statement

The results of this study will aid ASBAHT, Child-Help Tanzania, and Child-Help International in improving their existing CIC training programs and will contribute to the sparse literature on the implementation of CIC programs in resource limited settings. This will inform the improvement and continued expansion of continence management trainings by these organizations and others throughout sites in Tanzania, other East African countries, and beyond.

CHAPTER 2: BACKGROUND

Neural Tube Defects

Neural tube defects are congenital abnormalities affecting the brain, spine, or spinal cord. With approximately 300,000 newborns born with neural tube defects each year, they are one of the greatest causes of childhood mortality and disability-adjusted life years globally.[1] Worldwide, Spina bifida, one of the two most common forms of neural tube defect, is caused by incomplete closure of the neural tube early in pregnancy.[2,3] The major cause of spina bifida globally is inadequate blood folate levels in women of reproductive age, and evidence shows folic acid prevents a large proportion of cases of these birth defects.[4,5] Widescale fortification of flour with folic acid has been proven to be a safe and effective measure to reducing the incidence of spina bifida and other neural tube defects in multiple settings.[5,6] If implemented effectively worldwide, fortification of staple foods with folic acid could prevent 96% of all cases of neural tube defects. In the post-fortification era, the prevalence of neural tube defects in the United States decreased from 10 to 5 per 10,000 live births.[6]

Prevention of NTDs in Tanzania

In low and middle income countries (LMICs), the burden of birth defects in general is particularly high, with 94% of severe birth defects occurring in these countries.[1] There is an epidemic of folic acid-preventable spina bifida in Tanzania, with neural tube defects occurring at a rate of 13 per 10,000 live births.[2,6] Flour fortification is a compelling, cost-effective intervention, and the economic case remains strong in LMICs, where the cost per disability-adjusted life year is less than other frequently-used lifesaving public health measures in Tanzania, such as insecticide treated mosquito nets.[7] Although flour fortification is legally mandated in Tanzania, program coverage remains low. In sub-Saharan Africa, availability and use of commercially processed and fortified staple foods is particularly low in rural areas, where two-thirds of Tanzanians live.[7-10]

Supplementation of 400 micrograms of folic acid is recommended for all women of reproductive age globally via multivitamin supplements or the consumption of fortified foods.[11] Following the World Health Organization's recommendation for supplementation of folic acid during pregnancy to prevent anemia, this supplementation is offered in antenatal clinics in Tanzania.[12,13] Adherence to supplementation, however, was low, with only 20% of pregnant women receiving care at a major referral hospital in northern Tanzania reporting use of supplements during pregnancy. A variety of factors may be associated with non-use, including lack of knowledge of the importance of the supplements, fewer antenatal clinic visits, and lack of reliable availability of the drugs.[12,14]

For folic acid supplementation to effectively prevent NTDs, it must be used prior to pregnancy and within the first month of gestation, before closure of the neural tube. Attendance at antenatal clinics before conception and early in pregnancy, during this critical period, is notably low, with less than a quarter of Tanzanian women initiating prenatal care before their fourth month of pregnancy.[10,15] Barriers to early care seeking include socio-cultural beliefs, such as a reluctance to disclose pregnancy early on, and health system factors, including staff shortages and the requirement that male partners accompany expectant mothers to clinic.[16,17] Results from a study conducted at a tertiary referral hospital in northwest Tanzania showed that only 15% of mothers studied had used folic acid during the first trimester, and birth defects were significantly associated with non-use.[18]

Early Detection and Management

In addition to the lack of early folic acid supplementation during pregnancy, women carrying babies with spina bifida in Africa are unlikely to receive prenatal diagnosis, with diagnosis instead typically made at the time of delivery.[19] This contrasts to the United States and other higher-resourced settings, where prenatal ultrasounds and screening for elevated maternal serum alpha-ferroprotein levels are effective and widely available methods for fetal identification of neural tube defects.[20] In North America and Europe, termination of pregnancy following prenatal diagnosis of this defect is widespread, occurring in 63% of cases. Termination of pregnancy was associated with earlier gestational age at diagnosis and increased severity of the defect, and was more common in Europe than North America.[21]

In cases where the pregnancy is not terminated, fetal surgery is becoming a more widespread option for avoiding the progressive damage that occurs throughout gestation and improving outcomes.[22] Positive outcomes associated with intrauterine surgery include the reversal of hindbrain herniation and a decreased likelihood that shunt placement will be necessary after birth.[23] Management of spina bifida in neonates who have not undergone fetal surgery traditionally involves surgical repair within 48 hours for those with myelomeningocele, the most severe form of the defect, where the spinal cord and nerves are contained in a fluid-filled sac outside of the body. This quick repair is done to avoid infection, with meningitis a particular concern. Surgical management is also initiated shortly after birth for the majority of neonates with spina bifida who require ventriculo-peritoneal shunts to drain cerebrospinal fluid.[24]

Early detection and surgical treatment is one of the most important factors in reducing mortality and long-term disability associated with spina bifida, but the implementation of early surgical intervention remains a challenge in Tanzania and sub-Saharan Africa in general.[25] A 7-month study of 125 infants with neural tube defects operated on at Bugando Medical Center in northwest Tanzania showed that prenatal diagnosis and early surgery are still major challenges in this context, with only 7% of mothers receiving an ultrasound during pregnancy and a median age at shunt surgery of 137 days.[26] With only 5 neurosurgery centers able to perform operations for spina bifida in Tanzania, the barriers to early neonatal surgery are numerous. Delayed presentation is compounded by difficulties of accessing surgical centers, including distance, poor roads, lack of transportation, and direct and indirect costs.[19,27,28]

Despite medical advancements that have improved survival rates, increased mortality remains a major challenge for neonates, children, and adults with spina bifida globally.[3,29-34] Compared to the general population, those with spina bifida have a lifetime risk of death that is 10 times higher.[3] Approximately 80% of infants born with spina bifida survive the period immediately after birth, and approximately 90 percent of those children then survive the first year, with survival positively associated with a higher birth weight, older gestational age, and older maternal age.[3,30,33] Risk of death remains high during the first five years of childhood, and a third of children with spina bifida die by age 5, with common causes including pneumonia, hydrocephalous, cardiac problems, and other infections.[3,30] For individuals with the birth defect who survive childhood, mortality remains elevated throughout adulthood. Renal failure, infection, cardiac failure, and hydrocephalous are common causes of death in adults with spina bifida.[30-32]

Long-term survival analysis of individuals with spina bifida in Tanzania has not been reported. Data from studies examining survival outcomes after myelomeningocele repair in Uganda showed an overall under-5 childhood mortality rate of 37% and a 10-year survival probability of 55%.[25,35]

Children and adults with spina bifida face numerous complications affecting their quality of life and physical, social, and cognitive function.[32,36-39] Among these issues, some of the most prominent include varying degrees of cognitive impairment,[32,37] mobility limitations,[38] and bladder and bowel dysfunction.[39]

Bladder and Kidney Implications

Bladder dysfunction is of particular importance as it is closely linked to renal damage, the largest cause of morbidity and mortality in patients with spina bifida. Children with spina bifida frequently present with a neurogenic bladder, which is dysfunctional in the storing and emptying of urine. Left untreated, neurogenic bladder leads to kidney failure in half of patients by 5 years of age.[40] The use of Clean Intermittent Catheterization (CIC), a method of draining urine from the bladder at regular time intervals to prevent urine build up, is effective treatment that helps preserve kidney function in patients with neurogenic bladders and has greatly improved outcomes since its initiation in 1972.[41-43] When used in combination with antimuscarinic drugs such as oxybutynin, often administered to help relax the bladder, CIC reduces the development of renal damage in 90% of children and allows 85% of children to achieve social continence.[44-47]

Clean Intermittent Catheterization in Tanzania

In low-income settings, chronic kidney failure has been reported in childhood, likely as a consequence of failure to initiate or sub-optimal management of CIC.[48-50] Modern methods of treating end stage renal disease, such as urological surgery, dialysis, and transplantation are not widely available in Tanzania and other low-resourced settings, making the prevention of disease with use of CIC critically important.[46,48] CIC training programs are feasible in low-income settings and have existed in Tanzania since 2002.[46,48,51] Most CIC trainings in Tanzania take place in cooperation with large referral hospitals in major urban centers, including Dar es Salaam, Mwanza, and Arusha, and Stone Town on the semi-autonomous island of Zanzibar. Several non-governmental organizations, including the Association for Spina Bifida and Hydrocephalus in Tanzania (ASBAHT) and Child-Help Tanzania currently provide these trainings on a regular basis.

Evaluations of successful components of CIC training programs for patients with spina bifida exist,[52] but evaluations of these programs for in resource poor settings are limited and there have not been such assessments conducted in Tanzania.[51] In quality of life studies in similar settings in East Africa, 74% of patients trained on CIC in Uganda were found to have abandoned the practice.[53] An evaluation of CIC work in Tanzania is needed to better understand successful practices and areas of needed improvement to better the outcomes of successful CIC implementation in families of Tanzanian children with spina bifida and thus reduce kidney failure and mortality.

CHAPTER 3: METHODS

We conducted a qualitative study of parents of children with spina bifida in Dar es Salaam, Tanzania to understand their experiences at continence management trainings and facilitators and barriers to success implementing CIC following the trainings.

Study Population

The population studied was parents of children living with spina bifida in Dar es Salaam, Tanzania who had who had previously attended one or more continence management trainings through ASBAHT and/or Child-Help Tanzania, local support organizations for caregivers of children with spina bifida. The population lived in urban, peri-urban and rural settings within the city limits. Each was their child's primary caretaker and was heavily engaged in the day-to-day management of their child's continence.

Recruitment of Participants

Participants were recruited by staff of local support groups for caregivers of children with spina bifida. Program staff called parents using a convenience sample based on availability of contact information and briefly introduced the purpose of the study and provided the contact information of those interested to the study team. Seventeen parents participated, 16 mothers and one father. One additional parent wished to participate but was traveling during the study period and dropped out. Diversity was sought in age of child, sex of the child, level of disability, the time elapsed since the training, and the organization that provided the training.

Data Collection

The principal investigator (PI) and 2 co-researchers conducted semi-structured qualitative interviews in Swahili, with 17 parents regarding their successes and challenges with continence management, impressions of the training(s) they had attended, and other issues related to the care of their child with spina bifida. Interviews were conducted using an interview guide (see Appendix A). Care was taken to use a “blame-free” interview style, allowing families to speak freely of the challenges they have faced without worrying about facing retribution. All three interviewers, two males and one female, are fluent in Swahili and have experience doing qualitative interviews in Tanzania. One of the interviewers, a Tanzanian medical practitioner who was selected due to extensive previous experience conducting qualitative interviews for non-governmental organizations, was present at all interviews to ensure accuracy in understanding cultural nuances. It was explained to participants that the purpose of the interviews was to investigate continence management trainings and provide recommendations to implementing organizations to improve program offerings. Participants did not know interviewers prior to the study and met interviewers for the first time face to face during the interviews. Interviews were approximately one-hour in length and took place at or near participants’ homes in a private place of their choosing. In several cases, infant siblings of the children with spina bifida were with their mothers during interviews but no other non-participants were present. The interview guide was pilot tested before use in the field and the team was trained to ensure uniformity in understanding and approach to the questions. No interviews were repeated.

Data Analysis

The interviews were conducted in Swahili. Field notes were taken immediately after interviews of basic demographic data and immediate impressions. Interviews were recorded, transcribed verbatim, and translated into English by a professional translator. The study team read and checked all translations and reverse translated a random sample of interviews to ensure quality. The interviews were then coded and analyzed by the PI using thematic analysis in MaxQDA version 2020.2. Preliminary codes were developed using a deductive approach based on an initial reading of transcriptions, and further codes were developed using inductive coding to capture additional themes. During the analysis it was determined that saturation had been reached when new information stopped being presented and data began to have repetition and redundancy to past interviews. At this point, no additional interviews were conducted.

Ethical Considerations

Prior to conducting each interview, the objectives and methods of the study were explained to each participant, and written, informed consent was obtained. Participants were given a copy of study overview and informed consent documents, which included names and contact information of the study team and Emory University Institutional Review Board (IRB). During audio transcription, confidentiality was preserved through omitting names of the participants and their children and any other personally identifying information. Confidentiality was respected during data analysis and reporting as well. All three researchers were trained the Collaborative IRB Training Initiative Program (CITI) training for human subjects research through Emory University. The Emory University IRB granted approval for the study protocol (Study #00001711).

CHAPTER 4: RESULTS

Seventeen primary caregivers (16 female, 1 male) who had attended continence management trainings at four locations were interviewed. All interviewees were the parent of a child with spina bifida. The children range in age from two to fifteen years old and have varying degrees of disability. Most of the children were born with myelomeningocele, the most severe form of spina bifida with the highest potential for nerve damage The children with the lowest degree of disability had just a meningocele at birth, a type of spina bifida that involves less nerve damage to the spinal cord and usually causes less severe impairment. Those with the highest degree of disability had myelomeningocele together with hydrocephalous, a build-up of fluid in the brain that frequently causes brain damage.

The interview discussions focused on exploring the experiences at trainings and the barriers and facilitators to post-training success with continence management for the parents of children with spina bifida. During data analysis, positive and negative themes around training experience were identified along with 3 facilitator themes and 4 barrier themes were identified, together with corresponding subthemes, shown in tables 1-3.

Table 1: Experiences at Trainings

Positive Aspects
Teaching Methods
Building Peer Support
Negative Aspects
Missing Critical Pieces
Myths and Misinformation
Variation by Training Location

Table 2: Barriers to Successful Continence Management Post-Training

Lack of Systems
Follow-Up
Access to Training
Necessity of Self-Advocacy
Structural Barriers
Supply Chain
Mobility
School
Socioeconomic Challenges
Mother as Sole Caregiver
Lack of Paternal Support
Financial Difficulty
Employment

Table 3: Facilitators to Successful Continence Management Post-Training

Support Systems
Peer Support
Social Networks
Motivated Parents
Desire for Education for Child
Desire for Social Acceptance
Success with Stool Management
Finding Meaning
Program Acceptance
Organizational Support
Hope

Experiences at Trainings

Positive Training Experiences

The educational pedagogy and teaching methods utilized by the trainers were identified by parents as a primary strength of the continence management trainings. Repetition was utilized, both in the multi-day nature of the training and across repeat trainings that parents attended, and was cited as a major avenue for parents to develop confidence in managing their child's continence. Given the lack of consistent follow-up post-training, attending multiple trainings was identified as a way for parents to get support from experts to solve issues that arose after their first training. The practical, hands-on sessions offered at the trainings, where doctors and other trainers would watch a parent catheterize their child and offer over-the-shoulder support and guidance, were widely described as the most valuable part of the training. One mother explained, “It didn’t take long, because you are taught first with words and then later you come to be taught practically and then you get to understand… the way to actually do it” [#3]. Issues that may prevented successful CIC uptake were identified during these practical sessions and solutions could be offered immediately. A further aspect of the teaching style that was identified as an important and positive part of the trainings was the personal characteristics of the trainers, particularly their patience. Parents described being initially intimidated to interact with doctors due to most parents’ background of limited formal education and the steep cultural social hierarchy regarding experts. This challenge was overcome as participants reported the trainers exhibited ample patience and remained calm if the parents would initially misunderstand things.

The other primary strength of the trainings identified by participants was the opportunity to build informal peer support networks. Meeting other parents at the trainings who were facing similar challenges was encouraging to participants. The isolation felt by parents raising a child with a disability was mitigated by the newfound understanding that they were not alone.

> “*[When we are together], you are not miserable. Because we are usually miserable, aah, why only my child! But then when we, like this, when we are brought together we see that so there are many of us. This problem is not mine alone… So, this disease is a*

> *normal thing. I thought it was just my child alone. It was hurting me. Aah.. where did I go wrong until this child became like this? So, it is a disease!" [#7]*

They reported forming informal support networks to exchange information and tips via phone calls and text messaging after the trainings. The social connections formed by children at the trainings were also cited by participants as a major benefit. Parents of older children and adolescents in particular identified the opportunity for their child to meet others with a similar condition as a life-changing part of attending a training. These new friendships allowed for the transmission of positive peer norms, including encouragement to self-catheterize, and a boost in self-acceptance. One mother explained the large impact this had on her child, "At the beginning, he was saying he was scared. At that time I had to force him to [catheterize]. But a good thing, we found a child of his age. As soon as they arrived [at the training] they became friends… So, his friend started to catheterize himself. You see? And my child was motivated, 'So it is true- even I, it is not just me alone, my friend is here and he manages.' He also said, 'I also will manage.'… I felt great comfort. He was also comforted" [#7].

Negative Training Experiences

The use of oxybutynin is a foundational component of CIC. The medication increases pressure in the bladder, which decreases the leakage of urine between catheterizations. Parents identified mixed messaging around oxybutynin as a confusing aspect of the trainings, with some trainers advocating for use of the medication and other trainers discouraging the parents from using it. One participant recalled a trainer telling her, "If you have been advised to use that [oxybutynin] then don't use it. It has effects, it destroys kidney and also it brings cancer. If you see many people have cancer, they are using that thing, that medicine" [#13]. In the absence of clear messaging, misinformation regarding oxybutynin was perpetuated in informal peer channels among parents. Without a clear understanding of whether they should adopt the use of this medication, none of the parents interviewed went on to use the medication long-term after training

Unclear communication regarding initiation of CIC in children with regards to age and circumcision status was another area that caused hindered positive experiences at trainings. Parents reported being invited to trainings only to be told upon arrival that their child could not undergo catheterization because they weren't circumcised yet or because they were too young. This frustrated parents, particularly those who arrived for a weeklong training only to be told it didn't apply to their child.

Self-catheterization was another critical component of continence management that was not emphasized at trainings, weakening the effectiveness of parents' ability to implement CIC with their child. Participants described their hesitation to begin teaching their children to self-catheterize, as they did not have the formal training to know if their child was ready for this step. In cases where the child did self-catheterize, it was identified as a major positive factor in successful implementation of CIC. One mother shared she had been discouraged from teaching her son to self-catheterize, "I was told not yet, five is too young, [but] I taught him and he likes it, he truly likes it" [#16].

Experiences at trainings varied widely depending on where the parents received their training. Continence management trainings in Dar es Salaam were primarily facilitated by two separate organizations and are held at multiple locations. Parents reported negative experiences at trainings held at one of these locations in particular due to lack of resources and material support. Poverty is a limiting factor for caregivers being able to attend these trainings and successfully complete them, particularly at a training location that does not provide basic supplies such as sheets, soap, enough food for themselves and their children, and mosquito nets. Multiple parents identified being asked to bring their own bedsheets as a major stressor, explaining that a family may only have one set of sheets and sleep in a communal family bed so the husband and children not attending the training are then be forced to go without. Parents expressed dissatisfaction with the lack of mosquito nets and reported that children had contracted malaria at trainings after sleeping without a net. A further concern regarding the integrity of some of the organization leadership at this training location was shared, "You find that a lot of assistance is being given [by outsiders], but our children are not getting it. It's like, our children are the ones bringing wealth to people… Visitors come, you are called to come, you who have children with hydrocephalus and spina bifida, so that when the visitors come they would see that such children are many [to attract donations]" [#6].

Barriers to Continence Management

Barriers to successful continence management identified by participants fell under several main themes: lack of systems, structural barriers, and socioeconomic challenges.

Lack of Systems

A lack of a systematized method for selecting which families would attend continence management trainings caused confusion among caregivers and created inefficiencies. Some parents had been invited to multiple trainings and others had only attended one time, and the age of children at first training varied widely as well, although the reasons for these differences was not known by the parents. Successful implementation of continence management after trainings was also significantly affected by a lack of systems for follow-up. Parents were particularly distressed by this lack of follow-up in cases where it had been promised but then never materialized.

> *"Sharing with [program staff member] he told me that I shouldn't worry, we shall deliver this. And while we were still at the training, he did see the child... But it happened that after the training, it is… communicating with the leaders of this organization ended right there. So, the support is that— I didn't get any assistance there. [Staff member] never called me" [#10]*

When faced with urinary tract infections (UTIs) and skin breakdown, common issues faced by the children of study participants, parents did not have a clear understanding of what they needed to do to access help for their child.

The lack of systems guiding access to training and follow-up created a divide in service quality between parents who felt confident to advocate for better service delivery and those who did not. Some mothers described calling organizations to request an invitation to a training, calling trainers for support after the trainings when they faced challenges, and asking trainers for help getting catheterization supplies. Caregivers who reported not knowing where to turn if they needed help or not feeling comfortable reaching out for support in this way had greater difficulty accessing resources and support for their child. Without systemic support structures in place, the onus was on individual parents to know that they could access greater levels of support by self-advocating, creating inequality in service delivery. A mother who struggled shared, “we don’t know where to get the [catheterization] supplies… because we had been given the tools the first time, but we were not told that when the tools get problems to call them” [#12]. Another mother, who felt comfortable self-advocating, reported, “this [trainer], I had her phone number and many times I call her if there is something. Sometimes I can ask her, ‘Sister, how come my child is like this and this?’ So I had that habit of taking her phone number and calling and asking her” [#17].

Structural Barriers

Parents spoke of the challenges caused by an unreliable supply chain, and frequently mentioned the financial and logistical difficulties of having to travel to multiple locations via public transportation, often while carrying their child on their backs, to search for catheterization supplies and medications.

Caregivers expressed distress with their inability to access mobility solutions for their children, such as wheelchairs and other assistive devices. A sequalae of consequences followed lack of assistive mobility devices, including wounds on the children’s knees and legs from crawling and an inability to play independently with peers. Hygiene was also affected, with parents reporting that they could not teach their child to self-catheterize when the child did not have a wheelchair and must crawl on the ground, as they would have no way to keep their hands clean in the bathroom. Furthermore, mobility impacted many children’s ability to access education.

The education system was another source of structural difficulties hindering successful continence management and general wellbeing. Parents unanimously reported difficulties accessing education for their children with spina bifida. Being refused access to neighborhood schools was a universal experience for participants, with mobility and continence challenges cited as major reasons given by headmasters and teachers that their child could not attend. For children able to enroll in school, numerous challenges persisted. Parents reported that the only way to get a teacher or aide to help their child catheterize at school was by paying them, which was outside of the financial capabilities of almost all of those interviewed. Because teachers did not offer support, parents discussed how they must come to the school every few hours to perform CIC on their children. This limited opportunities for mothers in particular to work outside the home. Parents expressed that finding private places to catheterize their child without other students watching was a struggle as well. Because the children were largely not dry in between catheterizations, most parents discussed the need to send their child to school wearing diapers. The inability to afford diapers was cited as a reason students frequently missed school.

Socioeconomic Factors

Caregivers described being unable to leave their child with anyone else, such as a nanny or a neighbor. Being the only one with the ability to catheterize the child and fear of stigma and discrimination were cited as common reasons. This responsibility of being the sole person who could help the child contributed to stress and a sense of worry over what would happen to their child if the parent became ill or passed away. The one father who was interviewed was also the sole caregiver of the child, as the child's mother abandoned the child shortly after birth. His comments around isolation, responsibility, and stigma were largely similar to the mothers' responses. For example, he shared, "Have the neighbors helped us? No. What kind of help do you think they would give you? That is, this problem is yours, you will deal with it yourself" [#1]. Participants commented that there is a need for community outreach and education efforts to reduce stigma and increase the levels of acceptance of children with disabilities.

In addition, the role as sole caregiver for their child prevented participants from accessing employment, particularly in the formal sector. This had negative implications on the family's economic situation as a whole. A mother with some higher education who couldn't work due to caregiving responsibilities shared, "I was failing completely on how to help him. I was failing. He was wearing diapers all the time. He could get dirty. The nannies don't stay. That is, you find that, I mean I myself am failing to do my things, honestly. You find you have just put your certificates [of education] inside, you cannot apply for a job. You fail to do anything. You just stay, you don't have anything you are earning" [#16]

Gender and family dynamics were also a barrier to successful continence management. Mothers reported that their husbands, who had not attended CIC training, did not understand or accept continence management and frequently obstructed their ability to provide this care for their children. Mothers reported that fathers of male children cited concerns about their sons' manhood, and that fathers of children of both genders expressed a desire for their child to just "be normal" and not undergo catheterizations or bowel washouts. This dynamic created intense intrafamilial conflict and detracted from quality of life for both children and parents.

> *“When I catheterize him, the father is there, he doesn’t encourage you. He had those discouraging words, ‘Is that how you insert the catheter for this child!? Can this child just be normal!?’ Frankly, those words were hurting me because I had already gone to the training and I had already explained to him… but every time I catheterize the child if he is there [he says], ‘I am fed up of raising this child, what kind of child doesn’t know how to go to the bathroom!? Doesn’t know how to walk!?’… Sometimes he locks us outside. ‘Go outside!’ I go out sometimes with the child at midnight until five o’clock he opens the door, ‘Forgive me, I don’t know what’”* [#17]

The combination of lack of paternal understanding and limited financial decision-making power by mothers created an additional struggle regarding financial negotiations. Mothers reported having to fight with their husbands to get access to money for transportation, hospital and pharmacy bills, continence supplies, diapers, and other disability-related costs for their child.

> *“When my child feels [sick]…I tell my partner to give me fare… When I tell her father that I want to go to [the hospital], [he says] ‘Just give her Panadol. This child gets sick every day. You see! Just give her Panadol’... I say no. Because the child is in pain. The child is unable to sleep, we better go to a doctor to find out what the problem is. It is a problem, to get fare I must fight. Until you start begging while you have carried your child leaving” [#6]*

Facilitators to Success with Continence Management

Facilitators to successful continence management identified by participants fell into three main themes: support systems, motivated parents, and program acceptance.

Support Systems

The child-to-child and parent-to-parent peer support networks developed at trainings continued to exert a positive influence on continence management implementation once families returned home. Parents expressed feeling deeply comforted that their children had made friends with other kids facing similar challenges and reported improvements in children's self-confidence and motivation. Especially in the case of parents of adolescent children, the forming of these friendships contributed to a decrease in resistance to participate in disability-related self-care activities by the adolescents. Support networks independently developed by parents outside of trainings also had positive impacts on parents' ability to successfully implement continence management activities. Although most parents reported being the sole person who could catheterize and take care of their child, there were exceptions. One mother discussed how much her life improved after she taught her oldest daughter how to catheterize her younger sibling with spina bifida. Another mother had taught the child's grandmother how to perform continence management on the child and thus was able to get occasional respite by leaving the child with the grandmother. Although relatively rare, these support networks when present were highly valued.

Motivated Parents

The high levels of motivation among parents to provide the best care possible for their children was an important facilitator to continence management success. Despite the structural, socioeconomic, and systemic barriers, many of the goals of the continence management training programs were achieved, and much of this success would be traced to motivated caretakers. There were multiple factors contributing to this motivation, including a desire for children to be educated and socially accepted, successes with some aspects of program implementation, and a sense of meaning.

The most common goal reported by caregivers was for their child to be able to receive an education. The value of schooling is well-understood, and parents expressed a hope that education would prevent their disabled child from suffering later in life. A participant explained, “I would like him to study… so he gets his own job, because this life that he has, without employment? It will carry him to a bad place” [#4]. Without continence management it is difficult or impossible for children to attend school, providing a strong motivator for parents to learn and adopt the needed behaviors. While urine continence remains a challenge for many families, children can be sent to school in diapers, but without stool continence attendance at school is impossible. Beyond attendance at school, parents were also motivated by a desire for their child to be socially accepted. Forming successful social bonds while dealing with stool incontinence in particular proved nearly impossible for children, and parents reported immediate improvements in the psychosocial realm after returning home from training and beginning to implement fecal continence management. Despite difficulties with urinary continence management, the successes with stool management in particular provided stark improvements in the social and economic burden faced by participants. Parents expressed that seeing this improvement in overall quality of life gave them strength to continue with the program despite other challenges.

A final and major factor in the high levels of motivation shown by parents was the sense of meaning they derived from overcoming obstacles related to care of their children with spina bifida. For some, there was a religious element to this meaning, with parents viewing the burden of caring for a child with a disability as a duty given to them by God: "In the community… they can look at him in another way, but for me, because he is my burden, I see, what can you do? Because he is my child, and God has already given me that test, I am obliged to accept it the way it is" [#1].

Program Acceptance

Organizational and staff support was widely accepted by parents and contributed to successful implementation of continence management practices post-training. In a context where there are very limited support structures in place for children with spina bifida, parents emphasized their thankfulness to have staff members from the training organizations care about their child. Personal connections with staff members developed at the training provided emotional and logistical benefits to the parents, which proved important when parents needed support to troubleshoot problems such as supply chain issues or access to care for UTIs. Furthermore, many parents discussed the importance of the hope they gained at the trainings. The discovery that a deeply challenging part of the families' lives could be improved allowed the parents to have hope that other challenges they are facing may not be permanent and could potentially be improved as well. One mother shared, “After the training, because I had learned CIC there during the training, when I arrived at home I had high motivation and speed. My happiness was great happiness. To see that the child will be dry, and will live safely, and will play with her peers, will be happy all the time” [#10].

CHAPTER 5: DISCUSSION

For this study, we conducted interviews with 17 parents of children with spina bifida in the greater Dar es Salaam, Tanzania area to better understand experiences at continence management trainings and evaluate the successes and challenges of these training programs. Parents identified both positive and negative aspects of the trainings themselves, as well as factors that hindered their successful implementation of continence management upon returning home and factors that facilitated successful implementation. These themes provide valuable insight into the challenges faced when conducting continence management trainings in low-resource settings, potential improvements to these programs to improve outcomes, and successes that can be built upon or replicated by other continence management training programs in similar settings.

Among participants in this study, the teaching methods used at trainings, in particular the use of repetition, was identified as a key facilitator to understanding and post-training success. This aligns with past research showing that repeated participation in intensive interventions for children with spina bifida were associated with dose-responsive improvements in mastery of medical tasks.[54] Other research involving these intensive "camp-based" training interventions for children with spina bifida also emphasize the importance of building peer support, with children who built social connections and worked on their social skills finding the interventions most successful.[55] This is congruent with our finding that the opportunity to build peer support networks was a foundational strength of the continence management trainings and opportunities to formalize these opportunities may be a worthy priority.

Participants reported a major challenge of the training environment was confusing and missing information, particularly surrounding oxybutynin use, self-catheterization, and early initiation to CIC. Previous studies show that all three of these areas are critical to successful continence management programs in other settings[42,46,56,57] and thus their inclusion and consistent messaging in the curriculums used in Dar es Salaam will be important to program improvement. That several participants reported receiving advice directly at odds with expert guidance is a major area of concern that must be addressed.

The importance of developing systemic solutions to the barriers presented in this study cannot be understated, particularly when it relates to the provision of consistent follow-up care post-training. A report on children undergoing neurosurgery for spina bifida and hydrocephalous in Uganda found that community-based rehabilitation in the form of home visits was a major factor in long-term outcomes, with children who did not receive this follow-up having mortality rates 3 times higher than those who did receive it.[35] Thus, consistent follow-up may be valuable not only to reduce parent frustrations and to improve success rates at implementing continence management but also to improve other health and survival based outcomes.

Mobility and inability to access assistance related to mobility was consistently identified by participants as a major barrier to successful continence management and overall quality of life, consistent with a previous study of parents of children with spina bifida in Uganda.[58] Organizations working to provide continence management training should thus not ignore mobility challenges, but instead can view work towards connecting children with assistive devices as within the scope of their projects. Another structural barrier faced by participants was ability to access education and practice CIC at school. Interventions elsewhere in East Africa aimed at reducing school-based structural violence towards children with spina bifida have shown promising results and may be worth adapting to the Tanzanian context as resources allow.[59]

Our study confirms previous work asserting that the socioeconomic challenges faced by participants in continence management programs in LMICs are steep and must be overcome in order to achieve maximum program success.[51] Previous work has shown that having a disability places a child at higher risk of abuse and neglect, and families with a child with spina bifida face higher levels of conflict and lower levels of cohesion, findings which are more pronounced among families of lower socioeconomic status.[60-62] In order to address these barriers to success, programming targeting and empowering fathers to be partners in their child's care may be valuable in building family cohesion. Economic empowerment activities, which have been introduced by organizations serving the participants in this study, should continue to be rolled out where possible and should be strengthened by the inclusion of start-up capital to minimize barriers to entry.

The desire for education and social acceptance contributed to participants' motivation to succeed in managing their child's continence, consistent with previous work in other settings.[63] Our findings regarding the importance of spirituality and finding meaning in caring for their children aligned with a previous study of Kenyan mothers of children with spina bifida, in which almost half had their spiritual lives positively influenced by their child's disability.[64] These motivating factors may be important when recruiting parents to attend trainings.

Results of previous work show that prognosis in spina bifida is strongly associated with parental hope.[65] The importance of the hope built in parents by these trainings cannot be written off as a less-tangible and thus less-important benefit; rather, it is one of the most valuable aspects of this training and may contribute to improved quality of life and general prognosis.

Public Health and Clinical Recommendations

<u>This study identified several areas of focus that should be addressed in spina bifida management programs in low income settings. They are:</u>

1. Prioritize follow-up for parents who aren't able to do practical, hands-on sessions at trainings (for example, if a child has diarrhea so their parent can't perform the bowel washout, or if difficulties occur catheterizing due to the child's anatomy). This can include home visits, facilitating follow-up at a referral hospital if more testing is needed, or an invitation to another training.
2. Program leadership should decide what messages they want to provide around oxybutynin use based on best practices and then provide training to all trainers to ensure consistent messaging. If ultrasounds are determined to be a prerequisite to oxybutynin use, a portable ultrasound machine could be brought to the training location as doctors are already available on-site and can test the children there.
3. Create a systematic way of informing parents of trainings and ensuring that all parents in the catchment area are included. Creation of a simple database with

parent names, phone numbers, and dates of any trainings they have attended is a good first step. Ideally, program staff would work with clinicians or social workers at the referral hospitals to inform all parents attending spina bifida clinics of the trainings.

4. Do not delay initiation of CIC due to age or, in the case of male children, lack of circumcision. Literature shows outcomes are improved with kidney function and psychosocial functioning when CIC is initiated as early as possible.[42,57]
5. In addition to creating systems that remove the need for self-advocacy to access equitable care, coach parents on self-advocacy during trainings. Messages such as, "you are the one who can help your child," "speak up if you need help," and "don't be afraid to call someone at the organization or hospital if you can't solve a problem" may be helpful. In addition to this encouragement, providing contact information equitably to all parents will help counter the cultural norms that sometimes prevent parents, especially mothers from less educated or more rural backgrounds, from speaking up.
6. To reduce isolation that comes from being the only one who can provide continence management care to a child, coach mothers at training on how to train a support person (such as an older sibling, father, grandparent, or trusted neighbor) to also perform CIC. Consider hosting trainings where a parent can bring a support person to also learn.
7. Offer support to fathers. Inviting fathers to special "dads-only" trainings that are not overnight to reduce the burden of attendance could provide valuable social support

and encouragement. Male doctors and fathers who are involved in their child's care should both be invited to provide positive social pressure and act as role models.

8. Provide locally made reusable diapers, which are widely available in Uganda and Kenya and are made of materials available in Tanzania. This is an opportunity for income generation if mothers can be trained in production. Reusable diapers will reduce the economic burden of purchasing diapers and may contribute to a reduction in skin breakdown, a common problem when children sit in wet diapers for hours at a time when parents cannot afford enough clean ones.
9. Provide guidance to parents about when the child should begin self-catheterizing. Ideally, this can include a checklist for parents to follow so they know when the child is ready (i.e. is the child able to wash their hands independently before doing CIC? Will the child be able to tell the parent if there is a problem like bleeding when they catheterize?).
10. SHIP ("Spina Bifida Interdisciplinary Plan") booklets are not commonly used in Tanzania. Small, laminated information cards can be used as a simple solution to solve commonly faced problems. For example, parents largely did not know the name of oxybutynin, so even parents who desired to use it are not able to go to the hospital and ask for it. A simple card with the name of medication and dose, along with phone numbers for a trainer or clinician to call with questions, would provide clarity.
11. Provide small pamphlets to parents that they can share with their families or neighbors explaining what spina bifida is and encouraging others to treat the child

normally. Parents requested this to help fight stigma among their wider community and increase acceptance of the child.

12. Compile information on schools in different geographic areas of Dar es Salaam where children with spina bifida have been accepted and had successful experiences and support with their continence management in the school environment. Information officers at implementing organizations exist to serve this function. Furthermore, some special schools (such as Uhuru Mchanganyiko and The Salvation Army School in the Dar es Salaam area) have been willing to advocate on behalf of children to improve access to neighborhood schools, and this resource should be made known to all parents struggling to access education for their child.
13. Clarify the protocol that parents should follow if they suspect a UTI in their child and explain the steps to parents at the training.
14. Provide more active support and programming to kids while their parents are trained on CIC. Camps for children with spina bifida have been shown to improve both social and physical functioning with statistical significance and these trainings are an opportunity to provide this benefit. Children benefit largely from peer support and mentorship during trainings but this isn't systematized, so many adolescents and older children miss out if they don't have peers their age at the training.
15. Mobility assistance cannot be ignored. Wheelchairs are available in Dar es Salaam through partner organizations but parents are not made aware of this, even when they ask their program staff for assistance. Charities such as CCBRT provide heavily-subsidized wheelchairs but navigating the assessment process can be a

challenge. Program staff can work with parents to access this service. Wheelchairs allow older children to be able to self-catheterize and improve quality of life for the entire family.

16. Program integrity is key. Commonly voiced distrust of specific staff members and widespread dissatisfaction with one training site, as well as widespread rumors of financial impropriety by the same organization need to be addressed immediately. Multiple parents described concerning allegations, including being asked to take pictures of their children posing with donations that they then have to return to the staff member. The importance of staff training and oversight will be critical moving forward.

Other Considerations

In addition to the above public health recommendations, several further considerations may also strengthen program offerings. Offering trainings during school breaks or on weekends will be helpful to parents who have many school-aged children at home and face difficulties attending overnight trainings when school is in sessions. Support offerings for siblings may also be a valuable addition to trainings. To improve access to follow-up care, parents should be provided support, including logistical assistance, to enroll all children in insurance schemes.

Strengths and Limitations

To our knowledge, this is the first comprehensive, qualitative evaluation of a continence management program in a low-resource setting. This study provides a comprehensive view of the parents' perspective both of the training itself as well as of implementing the CIC program at home following training. A variety of previously unexplored topics were introduced, including access to education for children with spina bifida and continence management needs and the interplay of socioeconomic factors and continence management in this setting. This work provides a foundation for future studies to build on as well as a basis for practical program improvements.

Limitations include the geographic boundaries of the study. Participants were limited to those living in the peri-Dar es Salaam area. Children with spina bifida living in rural areas further from urban centers likely face additional challenges not captured in this body of work. In applying recommendations based on this work, attention must be payed to local cultural norms which can vary by subregion and may affect acceptability of interventions.

Implications

There are many important implications of this work. Primarily, it reinforces the already-recognized idea that CIC is both possible and important in low-resource settings.[46,51] Furthermore, it identifies important barriers that need to be mitigated to ensure maximum efficacy. Early initiation of CIC allows minimizes kidney damage and improves psychosocial outcomes.[42] Targeting the already-established neurosurgical networks at referral hospitals as well as systematizing access to CIC training programs may allow for improved start times and thus outcomes. Mobility, access to education, and poverty cannot be ignored. Considering the hierarchy of needs faced by these families, it is unrealistic to expect maximally positive outcomes in continence management training programs when needs judged by families to be more foundational or important are not met. While the challenges faced by families in Dar es Salaam are great, the situation in more rural areas is likely even more challenging. Lessons learned and systems strengthened through improving urban care will likely contribute to improved outcomes for more rural families down the line. Finally, as there remains a very limited body of work on the topic and many important questions remain, further research is needed on CIC in low resource settings. Ongoing program evaluations assessing program improvements once recommendations are implemented would be particularly valuable to better understand which are most effective and practical.

Conclusion

The findings from this work highlight many strengths of the continence management training program in Tanzania. They provide lessons that may be useful for programs working to implement this type of training in similar low-resource settings. Overall, the findings reinforce that although doing this work in low-resource settings is challenging, it is possible and necessary. The findings also point to areas of the program that can be improved and refined to improve service delivery and efficacy in the Tanzanian context. Acknowledging the numerous barriers to successful program implementation in settings with limited resources such as this, there are many notable successes. Many of the challenges identified are possible to overcome with relatively low cost and reasonable measures. With these practical changes, the continence management training programs evaluated can improve their efficacy in changing the lives of children with spina bifida in Tanzania and similar settings.

A key takeaway is the importance of developing systems that can overcome the typical challenges faced in this environment. Clarity and consistency of messaging from all trainers, made possible by a clear curriculum and continuing education and retraining of trainers when needed will be an important first step. While some barriers will be difficult to resolve, a focus on feasible changes to improve the quality of and access to the most effective interventions is likely to have a significant impact on children's lives.

The lessons learned in this evaluation will provide valuable insight to improve continence management programs in Dar es Salaam and similar low-resource settings. Training offerings will be improved, particularly in the identified areas of weakness. Improved systems and follow-up will be a critical component. As more babies born with spina bifida survive into childhood in Tanzania and neighboring countries due to improved provision of neurosurgical services, continence management will continue to be an area of increasing importance to ensure these children have the opportunity to maximize their physical and psychosocial functioning. This evaluation will allow for the planning of future continence management programs to build on known successes and mitigate the challenges identified by parents.

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APPENDIX

Appendix A: Interview Guide

Interview Guide

Continence Management Trainings Evaluation

Caregivers of Children with Spina Bifida

Dar es Salaam, Tanzania

Introduction [post-Informed Consent process]

Hi! Thank you for agreeing to talk with me today. My name is _____ and I am working on a project to try to improve the trainings that caregivers receive on continence management. We want to learn more about what works and what doesn't work in these trainings so that we can make them better in the future. This interview will take about an hour. You can skip any questions that you don't want to answer, or you can decide to stop the interview at any time if you don't want to continue. I'd like to record this interview so that I don't miss anything you say, but no one will listen to the recording other than me and the other workers on this project. Is that okay with you? There are no right or wrong answers for any of the questions I ask you today, the goal is just to hear your honest opinions and thoughts. No one from ASBAHT/Child-Help Tanzania will hear what you say, and no one will be upset or blame you if you talk about challenges or things you didn't like about the training or the program. Do you have any questions before we get started?

Opening

What is your dream for your child?

(probes: health, social, school)

General Continence Questions

First, I will ask you some questions about your child's continence care in general.

How has your child's life been affected by their challenges with continence?

(probe: changes since the training?)

*For parents with a child in school: How has your child's experience been with continence management at school?

(probes: challenges, successes, unexpected things)

Does your child self-catheterize? What has that been like?

How do your friends/neighbors/family view your child and their continence situation?

Training Experience

Now, I'm going to ask you some questions about your experience at the continence training. Remember, please be as honest as you can, it won't hurt or offend anyone and it will help them to improve the trainings so that families can be better helped.

Please tell me what you knew about continence management before going to the training?

(probes: importance, desirability, fears)

Why did you decide to do the training?

(probes: influences, child's condition, goals for child, barriers)

What parts of the CIC training did you feel went really well?

(probes: What was most helpful? Favorite part? Can you give me an example of something you learned that you felt was really important?)

What would you change about the trainings?

(probes: What was hard to understand?, What was missing?)

What was your experience with the trainers?

(probes: what would the ideal trainer be like?)

Post-Training Experience

Thank you so much for telling me about your experience at the training! Now I'm going to ask you some questions about what it was like for you at home once the training was over. Remember, even though we are recording this, everything you are saying is private and the organizations will not be told your answers, everything you are saying is just for us to help us improve the trainings. Your honesty is so helpful to us as we try to improve, so the more you can tell us the better.

What was it like when you got home after the training and began doing the continence management by yourself here?

(probes: reality vs expectations, resources, support, challenges, use of oxybutynin medication)

What follow up support did you receive after the trainings?

(probe: what was most helpful?)

What would you change about the follow-up support after trainings?

(probes: supplies, issues that came up?)

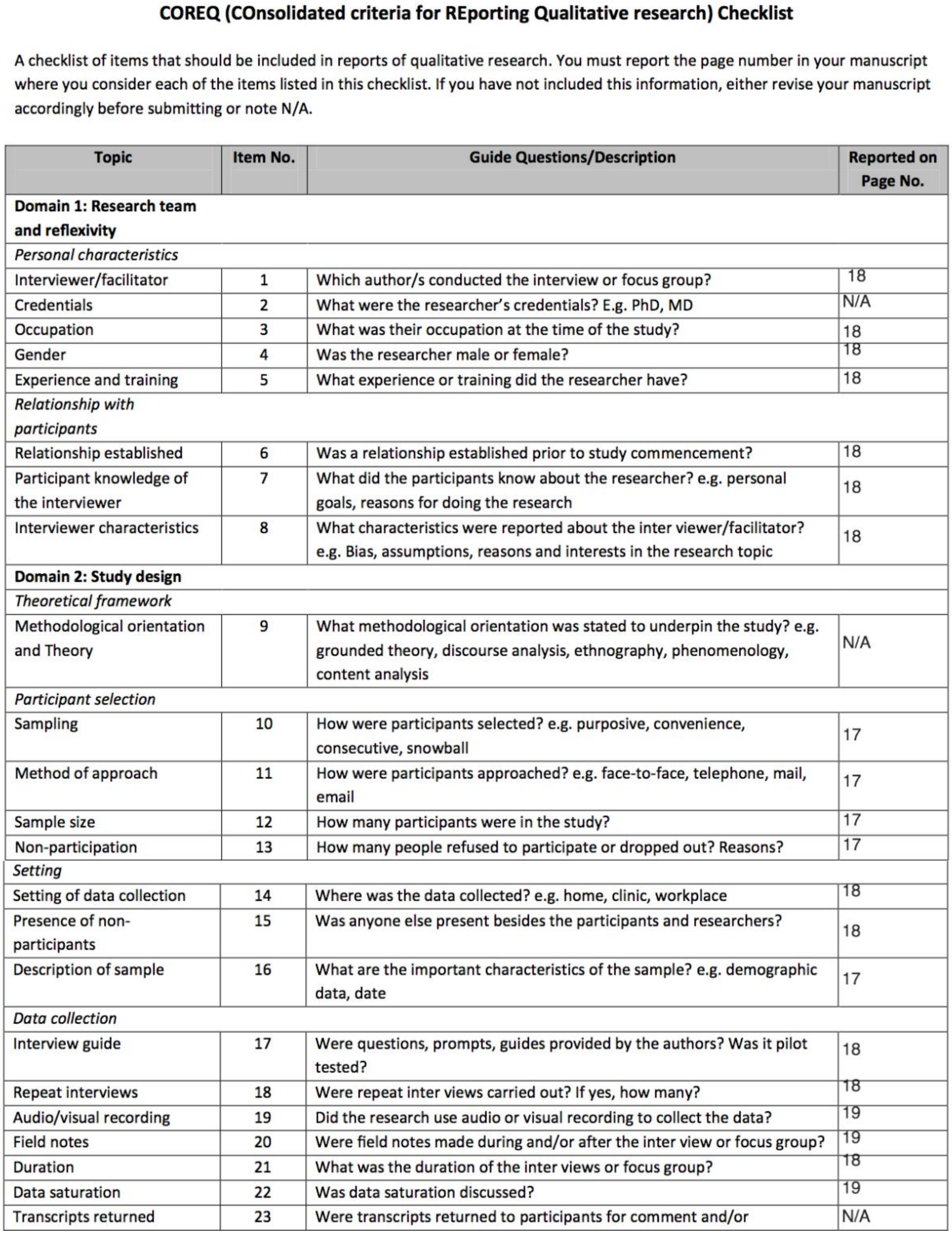
What would help you to have more success at managing your child’s continence care overall?

Closing

Thank you so much for your answers so far, this is very helpful. One last question for you:

What else do you want to share with us about your experience?

Appendix B: ISSM_COREQ Checklist



COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	18
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	N/A
Occupation	3	What was their occupation at the time of the study?	18
Gender	4	Was the researcher male or female?	18
Experience and training	5	What experience or training did the researcher have?	18
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	18
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	18
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	18
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	N/A
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	17
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	17
Sample size	12	How many participants were in the study?	17
Non-participation	13	How many people refused to participate or dropped out? Reasons?	17
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	18
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	18
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	17
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	18
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	18
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	19
Field notes	20	Were field notes made during and/or after the inter view or focus group?	19
Duration	21	What was the duration of the inter views or focus group?	18
Data saturation	22	Was data saturation discussed?	19
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	19
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	19
Software	27	What software, if applicable, was used to manage the data?	19
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	TBD
Data and findings consistent	30	Was there consistency between the data presented and the findings?	21
Clarity of major themes	31	Were major themes clearly presented in the findings?	21
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	N/A

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357