Developing an Assessment Tool for Post-Surgical Paediatric Rehabilitative Care in Tanzania: an Interprofessional Approach

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ABSTRACT

Purpose: Located in Arusha, Tanzania, The Plaster House provides rehabilitative services to children receiving surgical care for treatable disabilities. This article describes a set of outcome measurements developed in a collaborative relationship between an evaluation team from The Plaster House staff and St. Catherine University faculty, focused on effectively and efficiently collecting post-operative evaluation and outcome data from a rehabilitative care facility for children with treatable disabilities.

Method: From seven care pathways utilised for surgically treatable disabilities (cleft lip and palate, spina bifida, skeletal fluorosis, osteomyelitis, burns, clubfoot and hydrocephalus), an interactive process led to the development of a medical assessment tool for monitoring and evaluation with limited electronic health record and staffing capacity.

Results: The medical assessment tool serves multiple purposes for the rehabilitation programme, including monitoring participants' progress, evaluating the effectiveness of current practices, and sharing data with stakeholders. The tool includes collection of demographic and background information, one to three diagnosis-specific indicators to measure progress, and three questions related to typical development (activities of daily living, play, and social interaction).

Conclusion and Implications: Due to the delayed ability to conduct a site visit, the evaluation team relied heavily on effective communication to sufficiently relay challenges and successes in developing and implementing the tool. The proposed medical assessment tool developed by an interprofessional team has

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the potential to feasibly capture post-operative outcome measurements during rehabilitative care.

Key words: children with disabilities, medical assessment, monitoring and evaluation, outcome measurements

INTRODUCTION

Over 5 billion people lack access to necessary surgical intervention (Butler et al, 2017), and the majority of these individuals reside in regions of the world with small clinician to population ratios and under-resourced healthcare facilities (Philipo, Nagraj, Bokhary and Lakhoo, 2020). As a result, health inequities are present, as both socioeconomic status and public health infrastructure hinder access to adequate care, especially for those in remote areas (Taylor, Forgeron, Vandyk, Finley and Lightfoot, 2021). There are large numbers of children with surgically treatable disabilities, who go untreated each year (Butler et al, 2017; Hendriks et al, 2019). Infancy and early childhood are crucial time points for rehabilitative surgical interventions. When treatable disabilities are neglected during years of critical development, they have the potential to increase lifelong disability and contribute to early mortality (Butler et al, 2017).

In countries like Tanzania in East Africa, the shortage of surgeons and the handful of specialty hospitals and centres in a geographically large country severely limit the access to paediatric surgery (Butler, 2016; Lelli Chiesa et al, 2020). The number of surgeons, obstetricians and anaesthesiologists (SOA) falls short of the recommendations set by Tanzania's Ministry of Health, for 20 SOA per 100,000 population, with a ratio of 0.46 per 100,000 population (Ministry of Health Community Development, Gender, Elderly and Children, 2018; Philipo et al, 2020). In addition to training a larger clinical workforce, some Tanzanian hospitals and universities have formed international partnerships with universities and medical entities to reduce the burden of surgical need (Philipo et al, 2020). Additionally, non-governmental organisations (NGOs) fill gaps in paediatric surgical care and rehabilitation (Taylor et al, 2021). Faith-based missions, short-term surgical trips, academic partnerships, and teaching workshops have also played roles in addressing the paediatric surgical gaps in Tanzania (Butler et al, 2017; Hendriks et al, 2019).

The World Health Organisation (WHO) recommends the increased use of preand post-surgical assessment tools (World Health Organisation, 2021) to assure quality and appropriate client follow-up. Assessments and evaluations are an essential part of the perioperative plan of care. These assessments are often not a standard part of perioperative care in low-resource areas like Tanzania, as a lack of financial resources and trained personnel impede implementation (Butler et al, 2017). The lack of widely available pre- and post-operative assessments decrease the availability of data to measure progress and performance post surgery. Strengthening monitoring and evaluation data collection methods across a healthcare organisation or system often requires the implementation or the upgrading of electronic systems that can be used to capture the data (Luan, Mghase, Meyers and Chang, 2021). An additional barrier is the complexities of capturing data for measures of physical progress that require medical training and expertise (Hendriks et al, 2019).

While there are numerous global initiatives to increase access to paediatric surgical care and rehabilitation in low-resource areas, many of these are unpublished, creating an absence of literature on the subject (Lelli Chiesa et al, 2020). While standards of care have been set by the WHO for the intraoperative period, there is a paucity of provisions for perioperative care and rehabilitation. The use of perioperative assessment tools helps to ensure safety and promotes the success of various procedures in the long term. These assessments are not only useful for monitoring individual cases, but can be used to identify gaps and needs within systems themselves (de Oliveira Pires, da Luiz Goncalves Pedreira and Peterlini, 2013). Therefore, a need for the development of post-surgical medical assessment tools for infants and children in a rehabilitation centre in Arusha, Tanzania, was identified.

Project Description

Located in Arusha, Tanzania, The Plaster House provides rehabilitative care to children with treatable disabilities receiving surgical treatments at local hospitals. Working in partnership with local and international surgeons, the programme provides care to approximately 700 children annually, with an average daily census of 160 children. Infants and children up to 18 years, typically stay at The Plaster House from 4 - 24 weeks before and after orthopaedic surgery, plastic surgery, neurological surgery, or general surgery. Common conditions treated include clubfoot, cleft lip and palate, skeletal fluorosis, spina bifida and hydrocephalus, and burn scar contracture releases; less common surgeries include treatment for osteomyelitis, enlarged adenoids/tonsils, and anorectal malformations. While

at The Plaster House, children participate in occupational therapy, educational and play interventions, regular medical check-ups, and nutritional eating. The majority of children come from low-income households in the regional catchment area of northern Tanzania.

In June 2020, The Plaster House and an interdisciplinary team of health sciences faculty at St. Catherine University (St. Kate's) in St. Paul, Minnesota, developed a collaborative partnership. The primary purpose of the partnership was to develop a programme evaluation plan and assessment tools for The Plaster House. Over 18 months, the team went through multiple iterations to develop process, outcome, and impact objectives for each of the programme goals. The purpose of this paper is to describe the process of medical assessment tool development and provide samples of the assessment tools. This tool was designed to measure the achievement of one specific programme goal: to provide high quality, efficient, and effective individualised therapeutic care for children with surgically treatable disabilities and their caregivers, throughout their stay at The Plaster House. The phases of the medical assessment tool development are described. First, background information was obtained for each treatable disability served. In the second phase, a clinical assessment tool designed to monitor progress during the child's stay was conceptualised. Ultimately, a medical assessment tool, which includes diagnosis-specific outcomes and questions related to quality of life, was developed from the progress assessment tool.

Objective

Given the paucity of existing assessment tools applicable to limited-resource settings, this article aimed to fill a gap by providing sample outcome measurements for post-operative rehabilitative paediatric care, in order to effectively collect monitoring and evaluation data.

METHOD

Study Design

This is a descriptive study detailing the development of medical assessment tools to collect data on newly established programme goals. It is part of an overall programme evaluation conducted through a collaborative community-academic partnership between July 2020 and January 2022. The staff and faculty involved in the evaluation met virtually, twice a month, to develop project objectives and

develop assessment tools. The Plaster House team primarily included three occupational therapists, two medical attendants and a social worker. The St. Kate's team included faculty with the following disciplinary training: physician assistant, nursing, occupational therapy (OT), physical therapy (PT), nutrition, social work and public health. The collective group across both institutions is referred to as the "evaluation team."

Over the first four months, the evaluation team facilitated an assets mapping process with The Plaster House. Primary programmatic goals were established during the development of a logic model, one in which the medical assessment tool was designed to measure the objectives.

Medical Assessment Tool - Phase 1: Background

The initial approach of the assessment tool development focused on eight care pathways for commonly treated conditions already in place at The Plaster House. These included post-surgical care plans for cleft lip and palate, spina bifida, skeletal fluorosis, osteomyelitis, burns, clubfoot/neglected clubfoot, and hydrocephalus. These established care pathways defined the monitoring and evaluation process by listing required action steps, assigning The Plaster House team members to those actions, and creating an overall timeline for the pathway. The evaluation team initially considered the utility of developing measures according to different disciplinary perspectives (e.g., OT, PT, nursing, nutrition), for a child admitted under each care pathway but determined it was not practical.

Medical Assessment Tool - Phase 2: Design

Given that the similarities were identified for all care pathways, the evaluation team began creating a "rounding" tool that was somewhat generic but could be easily adapted to each specific care pathway. The team developed a pilot outcome-based rounding tool beginning with one specific care pathway: spina bifida. The tool examined three categories of outcomes important for this population: skin integrity, activities of daily living (ADLs) and quality of life. These were designed to be brief touchpoints that were easy to conceptualise as "improving", "maintaining", or "declining" at three time points: immediately post-surgery, during the rehabilitation phase at The Plaster House, and following discharge. When used during the rehabilitation phase, the tool could serve as a clinical progress assessment or rounding tool. The initial tool created for children admitted on the spina bifida care pathway is shown in Figure 1. Ultimately,

The Plaster House team determined that while the tool measured the identified items for outcomes, it was too labour intensive for their staff-client ratio, and not practical for routine use.

Figure 1. Pilot outcome-based rounding tool created for children with spina bifida.

	Immediate (at intake)	Short-term (upon discharge)	Long-term (follow-up interview)
Skin integrity	Are there any acute signs of infection?	Are the client and Mother able to verbalize signs and symptoms of infection?	Is the client able to maintain skin integrity/ free from infection while performing everyday tasks?
	Improving Maintaining Declining	Improving Maintaining Declining	Improving Maintaining Declining
Activities of daily living and functional mobility	Does the client attempt to engage in functional mobility and everyday tasks?	Does the client perform functional mobility and everyday tasks at an age appropriate level?	Is the client able to perform everyday tasks (age appropriate) while in their home?
	Improving Maintaining Declining	☐ Improving ☐ Maintaining ☐ Declining	Improving Maintaining Declining
Quality of Life	Client presents to be coping with transition to The Plaster House. Is the client demonstrating age appropriate play and interaction behaviors with peers and staff?	Does the client demonstrate psychosocial adjustment to increased function?	Demonstrate ability to advocate for needs/ wants
	☐ Improving ☐ Maintaining ☐ Declining	Improving Maintaining Declining	Improving Maintaining Declining

Medical Assessment Tool - Phase 3: Development

The final charge of the evaluation team was to create a medical assessment tool that included a single diagnosis-specific indicator for each care pathway and adaptable-to-age appropriate markers for progress. Even though the rounding tool conceptualised in Phase 2 for children with spina bifida was not practical, it served as a launching point for diagnosis-specific indicators in Phase 3. Instead of the original time points identified (post-surgery, during rehabilitation, and following discharge), the ideal assessment times were deemed to be intake and discharge, at minimum. The team reviewed international standards and peer reviewed literature to determine the most feasible and appropriate single indicator for positive change for each care pathway. Following consensus on indicators across all evaluation team members, The Plaster House team reviewed the chosen indicators to determine implementation feasibility and training needs for staff. The academic team created brief training materials and resources for these tools, and piloting began in January of 2022.

Data Collection

At this time, The Plaster House is using a free Electronic Health Record (EHR) system that has been adapted to their programme needs over the last two years. Ideally this medical assessment tool will be utilised through The Plaster House's EHR, simplifying the process for medical staff at The Plaster House. Given current challenges with the EHR software, the staff at The Plaster House are using Google Forms as an outside platform to collect data on client progress.

Ethics Approval

This study was approved by the St. Kate's Institutional Review Board #1547, St. Paul, 163 Minnesota, United States of America.

RESULTS

The medical assessment tool serves multiple purposes for the rehabilitation programme, including monitoring programme participants' progress, evaluating the effectiveness of current practices, and sharing data with stakeholders. It was essential to The Plaster House team that the medical assessment tool was easy to complete and export for analysis. The Plaster House will be utilising the final iteration of the medical assessment tool to track the outcomes of post-operative participants in the rehabilitation programme. The tool is primarily completed by occupational therapists, social workers, and medical professionals. Housed in Google Forms, the full medical assessment tool tracks age-appropriate markers and diagnosis-specific data to monitor the recovery and progress of children in the care of The Plaster House by completing the assessment at intake and discharge.

The medical assessment tool is best understood by dividing it into three sections. The first section collects demographic and background information. Demographic information includes name, medical record number, sex, tribe, and age. Background information includes a question related to the child's presenting diagnosis and nutritional status; a z-score (10 years of age) is collected, depending on the client's age. The second section of the medical assessment tool is diagnosis-specific. Each condition or care pathway has one uniquely defined indicator to measure progress. Commonly used measurements are utilised for a number of the diagnoses addressed in the second section of the medical assessment tool. For example, for burn scar contractures, the tool prompts the medical team to gather range of motion measurements at the involved joint, using a goniometer. These

measurements are recorded in degrees. For a child with clubfoot, the child's Pirani score is documented at diagnosis. The Pirani scoring system is frequently used to categorise and monitor progress of treatment for clubfoot (Mejabi et al, 2016). For children who present with hydrocephalus, the tool prompts the medical team to record the child's head circumference in centimetres. Wound measurements are gathered for children with osteomyelitis. These measurements are documented using length, width, and depth in centimetres.

When commonly used measurements or assessments failed to meet the needs of The Plaster House, the evaluation team designed unique questions. For example, if a child presents with a diagnosis of cleft lip, cleft palate, or palate fistula, The Plaster House team is prompted to assess the child's ability to self-feed at an age-appropriate level. The rating scale ranges from "no support" (eating and drinking well without adaptive equipment) to "intense support" (requires more than average help from the medical team, house mothers, or hospitalisation). Rankings in between include "mild support" (eating and drinking well with adaptive equipment and is progressing well) and "moderate support" (difficulty eating or drinking with adaptive equipment or not progressing well) as shown in Figure 2.

Cleft lip/cleft palate/palate fistula Medical Tool Score

Ease of feeding scale/support of feeding

Required for age appropriate support: *

No support (eating and drinking well with no adaptive equipment)

Mild support (eating and drinking well with adaptive equipment and is progressing well)

Moderate support (difficulty eating or drinking with adaptive equipment OR not progressing well)

Intense support (requires more than average help from med team, house mothers, or hospitalization)

Other:

Figure 2. A screenshot of a portion of the Cleft lip/palate/fistula tool in Google Forms.

The Plaster House staff document gait distance and level of assistance needed for children who present with skeletal fluorosis. The medical assessment tool contains fields to record the general distance the child can walk, with options including "household distances" and "community distances". The term "community distances" is defined by The Plaster House staff as being able to walk to and from the market, school, and church. The level of assistance required to complete functional mobility is documented using a scale that ranges from "No help, keeps up with peers, and can walk community distances" (Example: can walk to school without difficulty) to "No help but slower pace and/or cannot keep up with peers, shows signs of fatigue. It is difficult for the client to walk community distances" (Example: can walk to school, but it is difficult); and "Needs help. Cannot walk community distances. No participation in everyday activities. Can do home chores but not the outside chores" (Example: cannot walk to school, cannot herd animals, can walk within the home).

Lastly, for a child with spina bifida, bladder and bowel continence questions are utilised. The tool asks if the child is continent of bladder and bowel. If the child is incontinent of bladder or bowel, the follow-up question asks who manages the bladder and/or bowel incontinence. Answer options include "child managed", "parent managed", and "not managed". The current version of the medical assessment tool is shown in Figure 3.

Figure 3. The final Medical Assessment Tool collecting the child's demographic information, diagnosis-specific indicators, and age-appropriate interactions.

Club Foot Medical Tool Score: Pirani Score: Section One: Fluorosis Medical Tool Score: Can the child walk household distances? Plaster House Number: Can the child walk community distances? Is this assessment being conducted at: Level of independence: No help/keeps up with peers. Can walk community distances. (Example: can walk to school without difficulty) Intake Discharge · No help but slower pace/ cannot keep up with peers. Shows Other: signs of fatigue. It is difficult for the client to walk community distances. (Example: can walk to school, but it is difficult) Gender: Tribe: Needs help. Cannot walk community distances. No participation in everyday activities. Can do home chores but not the outside chores. (Select this option if the client needs Malnourishment Assessment (under the age of 10 years): help, regardless of how much help is needed) What is the patient's z-score? Malnourishment Assessment (over the age of 10 years): Hydrocephalus Medical Tool Score: What is the patient's BMI? Head circumference in centimeters: Patient Diagnosis: Osteomyelitis Medical Tool Score: · Burn scar contracture Wound dimensions (Length x Width x Depth) in centimeters: Cleft lip/ cleft palate/ palate fistula Clubfoot/neglected clubfoot Spina Bifida Medical Tool Score: Skeletal Fluorosis Is the client continent of bladder? Hydrocephalus Osteomyelitis Yes Spina bifida o No

Child managed Section Two: Parent managed Not managed **Burn Medical Tool Score:** Where was the measurement(s) taken? What was the measurement(s) Is the client continent of bowel? in degrees? Wrist flexion/ extension o Yes Range of Motion- Goniometer measurements: MCP and IP flexion/ extension Range of Motion- Goniometer measurements: Is howel incontinence: Elbow flexion/ extension Child managed Parent managed Range of Motion- Goniometer measurements: Not managed Shoulder abduction/ adduction Other: Range of Motion- Goniometer measurements: Shoulder flexion/ extension Range of Motion- Goniometer measurements: Hip flexion/ extension Section Three: Range of Motion- Goniometer measurements: Knee flexion/ extension Age-Appropriate Interactions Range of Motion- Goniometer measurements: is the client demonstrating age-appropriate: Ankle flexion/ extension Everyday tasks Range of Motion- Goniometer measurements: Yes Other: o No Range of Motion- Goniometer measurements: o Play o Yes Cleft lip/ Cleft palate/ Palate fistula Tool Score: No Level of support required for age-appropriate support: Social interaction with peers and staff No support (eating and drinking well with no adaptive 0 Yes equipment) Mo Mild support (eating and drinking well with adaptive equipment and is progressing well) Moderate support (difficulty eating or drinking with adaptive equipment OR not progressing well) o Intense support (requires more than average help from the medical team, house mothers, or hospitalization)

The third and final section of the medical assessment tool includes questions related to typical development to incorporate a biophysical model of assessment (World Health Organisation, 2002) that is completed for all children. The questions ask the medical team member to evaluate the child's ability to perform at an age-appropriate level in the areas of everyday tasks, such as ADLs, play, and social interaction.

Is bladder incontinence:

DISCUSSION

Currently, there are few examples in the literature on outcome measurement tools for post-surgical paediatric care in low-resource settings. The literature focuses primarily on client safety outcomes or quality of care centred around the time in the hospital (Butler, 2016; Lelli Chiesa et al, 2020; Philipo et al, 2020) or preparing for surgery (de Oliveira Pires et al, 2013), thus overlooking post-operative rehabilitation (Berry et al, 2019). It is noteworthy that there are diligent efforts to address client safety by the WHO in creating Global Patient Safety Action Plan 2021-2030, with a vision of prioritising safe and respectful care (World Health Organisation, 2021). A focus on translating evidence into actionable and measurable improvement outcomes for clients is presented by the WHO; however, there is no explicit statement for each time point of perioperative care.

One of the seven strategic objectives of the Global Patient Safety Action Plan is to, "Develop and sustain multisectoral and multinational synergy, partnership and solidarity to improve client safety and quality of care", in which monitoring and reporting is at the forefront (World Health Organisation, 2021). Luan, Mghase, Meyers and Chang (2021) note the importance of monitoring and evaluation in providing quality perioperative care. This medical assessment tool may begin to fill the gap as one example of an effective and efficient monitoring and evaluation tool for outcome data in the post-operative period.

In the development of the tool, successes and challenges of working with an international organisation in a low-resource setting arose. A strength of this project was the development of a medical assessment tool that was built as a response to a programme logic model, with the main outcomes focused on activities and outputs directed towards individualised, therapeutic care in all aspects of the programme (Field et al, 2018). Moreover, The Plaster House staff was directly involved in the tool development, as feedback on the plausibility of the tool was critical. Regular monitoring and communication across the evaluation team was required to ensure early identification of issues with the tool, resources available to adequately assess the outcomes for each child, and determine EHR capacity.

As a result of continuous communication, the medical assessment tool evolved through multiple iterations over 18 months. An example of this feedback loop is presented in the drafting of the tool. The second phase of the tool shown in Figure 1 was presented to the evaluation team and was deemed to be too laborious in a medical rounding scenario, resulting in the evaluation team bringing the idea forward for a single measurement outcome. Although The Plaster House was not able to use the design phase tool, it may be appropriate for use by other organisations seeking a more generalised tool for rounding.

The evaluation team observed that in the United States of America it is common to use complex and didactic processes, especially with regard to assessment in medical practice. One lesson learned is that elaborate assessment tools were not plausible for The Plaster House and perhaps are overly complex in U.S. settings as well. Studies have shown that simple, utilitarian tools such as checklists can improve quality of care and save lives (Gawande, 2011). Other research in Tanzania has focused on developing simple tools to monitor client outcomes post-operation. Abraham, Kahinga, Mapondella, Massawe, and Ntunaguzi (2020) documented the use of two post-operative outcomes, haemorrhage and infection rate, to measure success in adenotonsillectomy in Tanzanian hospitals. It was not

possible to evaluate data from programme activities already occurring at The Plaster House (Field et al, 2018), as minimal data was being collected. Therefore, in developing the medical assessment tool, the evaluation team worked together to identify one disease-specific indicator to support the general developmental progress indicators. These outcomes were chosen as evidence-based measures that would be easy to collect and reliable if different team members at The Plaster House collected the measurement, for higher inter-rater reliability. Simple and relevant measurements are necessary to minimise staff burden. The additional data collected will allow The Plaster House to collect baseline information to report to stakeholders.

Limitations

The limitations to this work are largely attributed to the St. Kate's team's inability to conduct an on-site visit due to the pandemic. This made it difficult to determine the use of the tool in practice. In this scenario, the faculty team relied heavily on effective communication with The Plaster House team to sufficiently relay challenges and successes with the tool. Additionally, not all NGOs have the staffing capabilities or EHRs to support data collection in the capacity that is being requested (Bach-Mortensen & Montgomery, 2018; Field et al, 2018; Luan et al, 2021). The EHR utilised in this case does not have the capacity to print reports, therefore the assessment tool had to be housed elsewhere, creating a barrier to ease of implementation and accessibility. Finally, the medical assessment tool has not been validated; instead it is supported by evidence-based progress indicators.

CONCLUSION

The medical assessment tool presented in this paper was designed for a unique model that The Plaster House is utilising in its post-surgical rehabilitation centre to advance monitoring and evaluation outcomes in children. The tool is intended to bring more effective and practical monitoring and evaluation of paediatric outcomes in low-resource settings such as Tanzania (Luan et al, 2021). It is specifically designed for monitoring children post-surgery for treatable disabilities such as burn contracture release, cleft lip/cleft palate, clubfoot, hydrocephalus, osteomyelitis, skeletal fluorosis, or spina bifida. Built from the framework of a logic model, the medical assessment tool focuses on the specific needs of The Plaster House in measuring their goal, "To provide high quality, efficient, and effective individualised therapeutic care for children with treatable disabilities

and their caregivers throughout their stay at The Plaster House." Using a logic model to improve health service outcomes is consistent with recommendations from parallel work (Field et al, 2018).

Monitoring and evaluation has proved to be a challenge where resources are limited (Luan et al, 2021). This could be attributed to lack of financial resources, technical capability and evaluation literacy, and/or challenges in identifying relevant evaluation systems and outcome indicators (Bach-Mortensen & Montgomery, 2018; Luan et al, 2021). This project has reiterated that The Plaster House was not an exception, as employee capacity and EHR difficulties present as barriers to monitoring and evaluation. While piloting is in process, Bach-Mortensen and Montgomery's key factors to promote monitoring and evaluation such as getting appropriate support, promoting a culture that supports evaluation, and providing motivation to be accountable to stakeholders (Bach-Mortensen & Montgomery, 2018) will be utilised to ensure the success of the tool. Moreover, by collecting measures during a rehabilitative stay, it allows for two time points to be measured and reduced loss to follow-up (Hendriks et al, 2019; Luan et al, 2021).

In conclusion, the medical assessment tool has the potential to capture practical outcome measurements for children with surgically treatable disabilities post-operation, during rehabilitative care, in low-resource settings.

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