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Perceived barriers and supports to accessing community-based services for Uganda's pediatric post-surgical population

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ABSTRACT

Background: Access to pediatric surgical intervention in low-income countries is expanding, but investments in post-surgical care have received less attention. This study explored the barriers and supports for school-aged children to access post-surgical, community-based follow-up care in Uganda as perceived by community stakeholders.

Materials and methods: This qualitative exploratory case study used in-depth, semi-structured interviews and in-country site visits among Ugandan organizations providing follow-up care to school-aged children in Uganda after surgery. Data from eight interviews and eight site visits were coded, analyzed, and cross-tabulated with a modified grounded theory approach.

Results: Four key barriers to community-based follow-up care were identified: discrimination, financial barriers, geographical barriers (including transportation), and caregiver limitations to support recovery. Three key supports to successful access to and participation in community-based post-surgical recovery were identified: disability awareness, the provision of sustained follow-up care, and caregiver supports for reintegration.

Conclusions: Increasing awareness of disability across local Ugandan communities, educating caregivers with accessible and culturally aware approaches, and funding sustainable follow-up care programming provide promising avenues for pediatric post-surgical recovery and community reintegration in contemporary Uganda.

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► IMPLICATIONS FOR REHABILITATION

- Multiple, intersecting factors prevent or promote access to post-surgical community-based services among school-aged children in Uganda.
- The most prominent barriers to pediatric community reintegration in Uganda include discrimination, lack of financial resources, geographical factors, and caregiver limitations.
- Community and interprofessional alliances must address disability awareness and sources of stigma in local contexts to promote optimal recovery and reintegration after surgery.
- Collaborative efforts are needed to develop sustainable funding for community-based care programs that specifically support pediatric post-surgical recovery and reintegration.
- Efforts to provide appropriate and empowering caregiver education are critical, particularly in geographical regions where ongoing access to rehabilitation professionals is minimal.

Introduction

Accessing community-based services to support recovery following surgical intervention can be especially challenging for children, who bear one-third of the world's disabilities [1–4]. In low- and middle-income countries (LMICs), the burden of surgical conditions among children is high and children who do not receive adequate care following a surgery risk long-term social and educational marginalization, as well as decreased quality of life [5–13]. Additionally, without appropriate follow-up care,

children face a potential decline in function post-surgery and may gain little to no surgical benefit [5–15].

The provision of adequate post-surgical follow-up care among children in LMICs is cost-effective and benefits children and their families [15]. However, the availability and affordability of follow-up care remain a challenge in LMICs [4]. Ensuring access to post-surgical follow-up care and rehabilitation to promote community reintegration and post-surgical participation among children is thus a significant priority.

Uganda is a landlocked country in East Africa with a population of 41.5 million, nearly half of which is younger than 15 years of age [16]. As a nation classified by the World Bank as low-income, Uganda is 76% rural and 19.7% of its population lives below the poverty line [16,17]. Health expenditures accounted for 7.2% of Uganda's gross domestic product in 2015, with nearly half of health-related expenditures being out-of-pocket payments [16,18]. The healthcare system of Uganda has two national referral hospitals, both located in the capital city of Kampala, with one providing pediatric surgical care. In addition, there are 14 regional referral hospitals and 139 district hospitals throughout the country that provide basic emergency surgery only [19]. Private hospitals and rehabilitation centers with specialties in pediatrics are a major source of pediatric care in Uganda.

Of the 14% of Ugandan children that need surgical care, roughly half receive treatment [20]. Trauma and congenital conditions carry both a high mortality rate and a high risk of lifelong disability [21]. LMICs like Uganda, however, often lack services that help facilitate community reintegration and ongoing recovery after surgical intervention to reduce the risk of mortality and disability [22]. As a result, families are often left without adequate information, training, and resources to care for their children, who depend upon familial support to reintegrate into their communities, and ultimately, to survive [23]. Since access to community-based supports is limited, parents may cope with their child's disability by only engaging traditional remedies [24,25]. Children thus face significant obstacles to successful recovery and community reintegration following surgical intervention.

Multiple studies have investigated the current rates of pediatric surgical intervention in Uganda [20,26–29] and the availability and scope of post-surgical rehabilitative services [12,30]. We previously examined the availability and geographic dispersion of community-based services and supports [30]; however, further understanding of barriers and supports to access is needed to determine priorities for policy change and improvement of sustainable community intervention. Examining barriers and supports goes beyond the identification of the availability of services alone, also considering critical factors such as education, training, and medical care as necessary components for both a child's individual development and social integration, two key outcomes identified in the World Health Organization's International Classification of Functioning, Disability and Health (ICF-CY) [31]. Therefore, we understand reintegration in this study as access to as well as meaningful participation in home, school, and community contexts following a pediatric surgical intervention.

The purpose of the present study is to explore – in collaboration with community-based organizations (CBOs) providing post-surgical resources for school-aged children (5–14 years of age) in Uganda – the perceived barriers and supports to follow-up care that supports community-reintegration by improving participation in home, school, and community contexts. This research is critical for addressing service access issues that negatively affect recovery and community reintegration among school-aged children in Uganda following surgery.

Methods and materials

An exploratory case study design was used to explore barriers and facilitators to accessing community-based services for recovery after pediatric surgery, due to the novel investigation topic and the need for an inductive approach [32,33]. Exploratory case study design also clarified priorities for future research and intervention. Data collection was conducted via semi-structured,

in-depth interviews to yield a rich description of the perceived barriers and supports. In addition, observational field notes during in-country visits to organizations provided contextual information.

In conjunction with the exploratory case study design, the study also employed a modified (constructivist) grounded theory approach, following the model proposed by Charmaz in the context of qualitative health research [34,35], in order to (a) propose practical and theoretical conclusions related to key themes and processes for barriers and supports to accessing community-based post-surgical pediatric care, and, (b) identify and advance contextually relevant priorities for future investigation [35]. Charmaz supports this approach of mixed and complementary methodology, especially as it prioritizes and helps clarify the key assumptions, beliefs, and meaning-making mechanisms of research participants [34].

Theoretical framework

This study engaged the ICF-CY [31] as a framework to identify key domains of community-based services to promote recovery and reintegration for school-aged children following surgery. Working from our study's understanding of reintegration as a social process concerned with access to and meaningful participation in home, school, and community contexts following surgical intervention, the researchers investigated four key domains (aligned with the “environmental factors” of the ICF-CY) that could promote or prevent community reintegration. The four domains explored in the present study were: (1) rehabilitation services; (2) assistive devices and technologies; (3) school reintegration programs; and (4) social or family support services. This theoretical alignment takes seriously the ICF-CY's call for “further research on environmental factors” to not only describe availability of resources supportive of recovery and rehabilitation, but further investigation into the processes of social integration.

Following the ICF-CY framework in our study, we defined rehabilitation services to include physical therapy, occupational therapy, and advocacy groups focused on disability sensitization and support for access to rehabilitative therapies. Assistive devices included medical (e.g., catheters), mobility (e.g., wheelchairs), and electronic devices (e.g., hearing aids). The school reintegration domain included organizations that provide advocacy and assistance in achieving access to educational institutions (i.e., financial assistance) as well as organizations that provide specialized educational services for children following surgery. Social support and family services included organizations that provide social services to families (e.g., food security programs, work training, family education), parent and caregiver support groups, parent and caregiver advocacy meetings (at local, country, and continent levels), and pediatric medical homes.

Participants

Using this framework, 126 community-based resources available to school-aged children after surgery in Uganda were identified with public data sources, internet searches, and directories of disability organizations compiled by the Uganda Society for Disabled Children (USDC), UNICEF's study on children with disabilities living in Uganda, and the Community Based Rehabilitation Africa Network (AfriCAN) [36–38]. Building on previous research quantifying the pediatric surgical burden in Uganda, these organizations provide support to school-aged children following surgical intervention to address masses, acute injuries/wounds, acquired deformities, burns, and congenital deformities [20]. Organizations

Table 1. Characteristics of organizations and participants.

Organization/ interview participant #	Interview participant nationality and sex	Participant's role	Assistive devices	Rehabilitation services	School re-entry	Social and family support	Region of Uganda
1 ^a	American – F	Physiotherapist	–	X	–	–	Central
2 ^a	Ugandan – F	Physiotherapist	X	X	–	X	Eastern
3 ^{a,b}	American – F	Executive Dir.	–	–	X	X	Central
4 ^{a,b}	British – M	Program Dir.	–	–	–	X	Eastern
5 ^a	American – M	CEO	–	–	–	X	Central
6 ^{a,b}	Ugandan – F	Parent of Child with Disability, Program Dir.	X	X	–	X	Western
7 ^a	Ugandan – F	Program Dir.	–	–	X	X	Central
8 ^a	British – F	Physician, Program Dir.	–	X	–	X	Central
9 ^{a,b}	Ugandan – F	Physiotherapist, Program Dir.	X	X	X	X	Central
10 ^b	N/A	N/A	X	X	X	X	Central
11 ^b	N/A	N/A	–	–	X	X	Eastern
12 ^b	N/A	N/A	X	X	–	–	Central and North
13 ^b	N/A	N/A	X	X	X	X	Central

F: female; M: male; Dir.: director; CEO: chief executive officer.

^aA formal qualitative interview was completed with a stakeholder from this organization.

^bA site visit and associated field notes were completed at this organization.

offering services solely for non-surgical conditions were excluded (such as services exclusively available to deaf or blind children and services exclusively providing pediatric HIV/AIDS care).

Among the total 126 organizations, 23 organizations with accurate, operational, and publicly available contact information were contacted for study participation. These 23 organizations represented all four geographic regions of Uganda and all four identified domains of community-based resources. An initial email was sent to these 23 organizations. If no response was received, follow-up was conducted in the form of a second email or a phone call, depending on available contact information. All initial and follow-up communications, as well as interviews and site visits, were conducted in English.

Individual representatives from nine organizations agreed to participate in formal interviews, with four of these organizations also agreeing to in-country site visits. Four additional organizations agreed to site visits alone. These participants represented a total of 13 distinct organizations across the Central, Western, and Eastern regions of Uganda (Table 1). Participants represented a broad scope of experience and knowledge, with both Ugandan and non-Ugandan perspectives represented. Organizations included children's homes, hospitals, rehabilitation centers, and educational centers. Each organization offered services and resources in one or more of the four identified domains in alignment with the ICF-CY "environmental factors." Furthermore, many of the organizations regularly collaborate with various medical and political bodies within Uganda, allowing them to provide insight into multiple influencing factors on post-surgical pediatric care.

Data collection

In-depth, semi-structured qualitative interviews were conducted using WebEx and Skype with individual representatives from nine distinct organizations and were recorded with participant permission. An interview guide (see Table 2) developed based on the ICF-CY framework was utilized by all researchers to standardize questions. Five researchers completed these interviews (SB, NK, AM, JS, and BW).

In addition, three researchers (AM, SO, and JS) conducted in-country site visits among eight organizations to collect observational field notes. Site visits lasted between one and four hours and consisted of the following: an unrecorded interview with one to four staff members and a tour of the facility. Observational

field notes were recorded by the three researchers on the following details pertinent to each organization: contextual factors, environmental factors, staffing, organizational flow, capacity status, and other observations of barriers and supports to successful community reintegration of a child after surgery (see Table 3 for field note guide developed out of the ICF-CY framework). Upon return, these field notes (three sets for each site) were electronically collated and transcribed. Following this process, the original notes were securely destroyed.

Data analysis

A modified grounded theory approach was engaged to provide a structured process for data analysis of the interviews and field notes [34,39]. Each of the nine recorded semi-structured interviews was transcribed verbatim. One interview was discarded due to technical issues with the data file that were unable to be resolved with professional assistance. The three sets of field notes from each of the eight site visits were collated by organization and electronically transcribed.

A three-phased coding process consistent with Charmaz's modified grounded theory approach was used to review key terms and themes across the data and to establish a codebook [34]. In the first phase, three researchers (SB, LB, and AP) used line-by-line coding to generate provisional codes representative of a wide range of theoretical meanings grounded in the data [34] (e.g., *in vivo* codes such as "this is not a curse"). In the second phase, focused coding [34] was employed to identify higher-level conceptual themes (e.g., exclusion). In the final phase, the researchers employed theoretical coding [34] to reorganize, clarify, and theorize about the relationships between prominent categories and processes in the data (e.g., discrimination with sub-codes for stigma, abandonment/neglect/abuse, prioritization of children without disabilities in religious and community settings, etc.).

Throughout the coding process, the researchers adopted a constant comparative method [34] in which they made comparisons among interview statements and incidents from the same participant, and later, among statements and themes from different participants. The initial codebook was extensively discussed and reviewed among all researchers who coded the data (including multiple readings and refinement of code definitions and parameters) for a period of two weeks, before the second and final phase coding was completed. The final codebook consisted

Table 2. Interview guide: questions to guide qualitative interviews with stakeholders.

Question 1	What resources or services are provided by your organization for children (5–14 years) recovering after surgery? From your website, we know you offer _____ (rehab, assistive devices, etc.) but can you describe in more detail the services you offer?
Question 2	What kind of care do children receive after surgery in Uganda currently? (i.e., to assist with activities of daily living, community participation, schooling, transportation)?
Question 3	In your opinion, what type of services are most important for children after surgery in Uganda to help with physical functioning, and participation in activities (personal and community)? Follow-up: Out of the services you identified, which service type do you think there is a lack of in Uganda? In other words, what is the most important kind of service that is least available for children currently?
Question 4	What do you think are the obstacles to recovery and full participation in activities (individual and community) after surgery for children? a. What do you think are major personal and environmental factors that cause positive recovery after surgery (i.e., socioeconomic status, gender, education, age, distance from clinic, ethnicity, support, cultural norms, transportation, etc.)? b. What do you think are major personal and environmental factors that cause poor recovery after surgery? c. What are the main personal and environmental factors that cause positive community reintegration for children after surgery? d. What are the main personal and environmental factors that cause poor community reintegration for children after surgery?
Question 5	How do you believe patients learn about your services/organization or are referred to you? Follow-up: Does your organization have capacity to work with more patients than it currently is, or is it operating at maximum or over capacity?
Question 6	Where do you generally discharge patients when they leave? Follow-up: What makes it difficult to discharge a patient (i.e., home, long-term facility, hospital, etc.)?
Question 7	What do you think [NGO and nonprofit organizations] do well in helping children transition from surgery back into their communities? What do you think they don't do well? Follow-up: Same question as above (and as applicable) for: government organizations, community-based groups, and medical centers (clinics, hospitals)
Question 8	Who do you consider to be the most important stakeholders, advocates, and/or providers for children to receive the best follow-up care and community reintegration following surgery?
Question 9	Do you have a relationship/partnership with other organizations/clinics/hospitals? Follow-up: How was the partnership initiated? What were those first months/years like? How has it progressed? Have you tried to reach out to other organizations? If not, why not?
Question 10	Is there anything else you would like to share?

Table 3. Field note guide: framework to guide field note taking after site visits in Uganda.

Contextual factors	At a national and regional level: cultural values and differences in socioeconomic and geographic influence of service availability in support of recovery and community reintegration.
Environmental factors	At an organizational level: the space layout, equipment present and its availability and accessibility, architectural supports, barriers and facilitators to service delivery, safety barriers and supports, staff awareness of similar organizations, and geographic proximity with similar organizations.
Staffing	Organization of, recruitment, retention, and training.
Organizational flow	Marketing/outreach strategies, referral, intake and discharge processes.
Service capacity	Currently at or beyond capacity, ability to take on additional service recipients, barriers and supports for managing staff to child ratio, rate limiting factors to increase capacity.

of identified codes, sub-codes, definitions, examples, and exclusions.

All researchers practiced coding with a sample data set and received detailed feedback from the primary investigator trained in qualitative research. The researchers agreed stylistically to code at the sentence level or multi-sentence level with the goal of resisting fragmentation of key categories and processes emerging from the data, consistent with Charmaz's recommendations for coding in a modified grounded theory framework [34]. Throughout the coding process, researchers communicated frequently to clarify aspects of the codebook and resolve differences in coding approaches. Using the final codebook, teams of two researchers coded the same four interviews and set of four site visit notes. The primary investigator coded all interviews and all site visit notes; as a result, three researchers coded each interview and each site visit note collection.

Data saturation was also determined per an inductive saturation process [34,39]. Three interviews were initially used to draft the preliminary codebook. Additional themes were added to the codebook upon analysis the remaining five interviews. As the final two interviews were coded, researchers confirmed that there were no additional emerging themes, categories, and relationships not

already included in the codebook. Consistent with a modified grounded theory approach, saturation parameters were satisfied based on the emergence of no further properties of key themes, categories, and theoretical relationships emerging from the data [34]. The multiple disciplinary and research backgrounds among the co-authors supported determination of the achievement of data saturation [40].

Data were analyzed using NVivo Qualitative Data Analysis Software (Version 11, QSR International, 2017). The coding was assessed for percent agreement using a coding comparison query in NVivo following completion of all coding; the team achieved 90% percent agreement across all coders for each theme, demonstrating resonance in coding approach and results.

Once all coding was complete, each piece of text associated with a code (e.g., "finance" or "awareness") was then labeled as either a "barrier" or a "support." The research team then cross tabulated the codes to identify the most prominent barriers and supports to accessing care to support community reintegration for school-aged children post-surgery in Uganda, across interviews. Consistent with a modified grounded theory approach, a literature review was conducted after first completing the results section to avoid importing preconceived ideas to the analysis [34].

Ethical considerations

This study was approved by the Duke University Campus Institutional Review Board. All interviewees provided verbal consent prior to participating. To ensure confidentiality, all recordings and field notes with identifying information were saved on a server with encrypted VPN access and password protection. All person-level identifiers were removed prior to analysis.

Results

We identified four key barriers (discrimination, finance, geography, and caregiver limitations), and three key supports (awareness, sustained follow-up care, and caregiver support) for accessing community-based resources for school-aged children following surgery in Uganda. These seven themes emerged across all four domains of community-based services and among interviewees of Ugandan and non-Ugandan nationality. In what follows, we define each of the barriers and supports, featuring the most notable quotations from interview participants, as well as excerpts from field notes, to provide a more holistic illustration of each major theme.

Perceived barriers (see Table 4) for summary)

Discrimination

We defined “discrimination” as implicit or explicit reports of attitudes, perspectives, and behaviors that exercise prejudice against children post-surgery. Three sub-themes of discrimination arose from the interviews and field notes: cultural discrimination (cultural beliefs surrounding disability and medical conditions related to surgery), educational discrimination (prejudice exercised in school contexts or barriers to accessing education), and more extreme behaviors of discrimination including abandonment, neglect, and abuse. All three sub-themes were identified as barriers for children to receive post-surgical care. During in-country site visits, all eight sites identified discrimination toward children following surgery as a barrier to community re-integration following surgery.

Cultural discrimination was often associated with references to disability being perceived as a curse, including references to witchcraft and to parents turning to witchcraft practitioners:

Parents think this is like a demon – being demon possessed. It’s a curse. It’s a problem. – Participant 6, a Ugandan parent of a child with disability; program director

Understanding the spiritual complications in this culture are difficult coming from the West...somebody really might have consulted a witch doctor and the witch doctor asked for a sacrifice and the family could have chosen to have the child killed or have them disabled. – Participant 1, an American physiotherapist

Cultural discrimination also encompasses negative attitudes about disability that impact how children are perceived when

they return to their communities following surgery. Educational discrimination pertains to the challenges children face when trying to return to school within educational systems that are often under-equipped to accommodate students after surgery. Field note data suggested that bullying can accompany educational discrimination.

We don’t have a lot of special schools—like special for kids with disabilities. Or if they are there, they are not very accessible... [they are] usually in the urban areas and very expensive as well. – Participant 2, a Ugandan physiotherapist

Discrimination also includes references to abandonment, neglect, and abuse. For example, multiple field notes and interview participants reflected on the common reports of parents “hiding children away” following a surgery.

We’ve heard awful stories of how disabled children can be treated by parents, family members, and communities. Stories of children being tied up, stories of children not being fed, stories of children just being left. – Participant 4, a British program director

Finance

We considered finance as discussions about monetary resources as they relate to accessing post-surgical community-based care. Four interview participants noted that families in poverty struggle to afford follow-up care, especially when they have multiple children. Field note data also affirmed this conclusion, with five site visits emphasizing the detrimental effects of poverty. Children recovering from surgery may become less of a priority for families due to financial limitations.

Socioeconomic status is a huge [barrier] because there is no insurance system. So you have to be able to afford the follow-up therapy. – Participant 3, an American executive director

The second obstacle is poverty. When you look at the cost of rehabilitation, it is expensive for them. Remember they don’t have only this one child. Other children also have needs. – Participant 7, a Ugandan program director

Specifically, interviewees and field notes revealed that many post-surgical services were unaffordable for families with a low-socioeconomic status, particularly assistive devices, specialized education, and rehabilitation services.

The biggest problem is the kids being able to pay for assistive devices... in most cases they are very expensive, and so it is very hard for the caretakers to get them. – Participant 2, a Ugandan physiotherapist

Even when non-profit hospitals cover the majority of surgical costs, many families still cannot afford the remaining expenses. Resonant with both interview and field note data, this difficulty with affordability was often attributed to family structures of single mothers.

Table 4. Barriers: most coded themes and sub-themes regarding barriers to service access in qualitative interviews and field notes.

Theme	Subtheme(s)	% of interview participants that mentioned subtheme	% of organizations with theme noted in field notes
Discrimination	Cultural discrimination	75% (<i>n</i> = 6)	75% (<i>n</i> = 6)
	Abandonment, neglect, and abuse	50% (<i>n</i> = 4)	37.5% (<i>n</i> = 3)
	Educational discrimination	37.5% (<i>n</i> = 3)	50% (<i>n</i> = 4)
Caregiver limitations	Lack of understanding of information	75% (<i>n</i> = 6)	37.5% (<i>n</i> = 3)
	Lack of training and education	50% (<i>n</i> = 4)	37.5% (<i>n</i> = 3)
Finance	High cost for services	50% (<i>n</i> = 4)	50% (<i>n</i> = 4)
	Low SES	50% (<i>n</i> = 4)	62.5% (<i>n</i> = 5)
Geography	Transportation challenges	87.5% (<i>n</i> = 7)	62.5% (<i>n</i> = 5)
	Rural settings	50% (<i>n</i> = 4)	25% (<i>n</i> = 2)

Bolded % not a primary barrier in field notes.

Even though the hospital pays for ward expenses...surgery and recovery is still too expensive for some of these mothers. – Participant 2, a Ugandan physiotherapist

Geography

This theme encompasses the relationship of geographical features of Uganda (rural vs. urban, village vs. city, populous vs. remote). Two major sub-themes of geography were apparent after analysis of the interview data: transportation and rural settings. Both of these subthemes were identified as barriers to receiving follow-up care. Transportation was described in seven interviews as a barrier due to cost and accessibility.

So many families cannot afford [follow-up care] – they can't even afford the transport to get to the hospital. – Participant 8, a British physician and program director

...the parent might say ...'oh you are too far, it is too expensive to do the transport to go to therapy. The kid is going to be fine anyway' and they just drop it. – Participant 3, an American executive director

Field note data from five organizations revealed inaccessible and unaffordable transportation as a particular barrier for children to consistently attend services to support rehabilitation, particularly physiotherapy. The lack of necessary transportation resources was another notable theme discussed in the interviews.

There are not very many ambulances in Uganda. They probably get to therapy by taxi [a 14 seat commuter van]...funds are incredibly short, even for something as simple as a taxi ride. – Participant 4, a British program director

Living in a rural setting was a major barrier to post-surgical recovery and reintegration, primarily as a result of an insurmountable distance to hospitals, rehabilitation settings, and access points for assistive devices. Four interview participants discussed this specific barrier, and field note data revealed this same concern among two organizations.

Out of the hospital, the biggest challenge for these children is rehab...most of the rehabilitation services are very far from where the kids stay. – Participant 2, a Ugandan physiotherapist

Caregiver limitations

This theme includes any general discussion pertaining to a parent or caregiver of a child with a post-surgical condition. Some organizations noted that caregivers often lack the training and education necessary to deal with post-surgical realities, most often, disability.

Lack of health education...lack of knowledge...the guardians in the villages, grandparents, or very, very poor mothers—they are very poorly educated. So, they really don't have any idea of the need for the post-operative care. That's the problem. – Participant 8, a British physician; program director

One interviewee added that caregiver training often clashes with cultural norms.

To educate the family is perceived as giving bad news, and nobody likes to do that here. – Participant 1, an American physiotherapist

Along with a lack of training and education, caregivers may also lack appropriate understanding or misunderstand information about their child's post-surgical status.

It's very hard, especially for children who have epilepsy. People don't even touch them when they have seizures. They fear them. They think this is an infectious disease which can affect them easily. – Participant 6, a Ugandan parent of a child with disability; program director

I do think that there is a psychological obstacle for parents to really understand that their child is now healthy [post-surgery] and able to do things that they were never able to do before. – Participant 5, an American chief executive officer

Additional interview participants suggested that the biggest information gap lies in the lack of understanding of post-surgery follow-up need among caregivers.

The biggest gap is parents understanding the importance of post-surgery follow-up, either with a doctor or at home. The importance of continuing to do therapy...the importance of then putting that child back in school. The importance of that child obtaining levels of independence. – Participant 3, an American executive director

The caregivers often don't have any idea of the need for post-operative care. – Participant 7, a Ugandan program director

Perceived supports (see Table 5 for summary)

Awareness

We defined "awareness" as any form of cognizance, understanding, or acceptance of post-surgical conditions and the available resources for children post-surgery. A commonly used term among the interview participants regarding this theme was "sensitization," which describes the process through which organizations disseminated information to local communities to foster awareness and acceptance. One channel for fostering this awareness included building reciprocal relationships between service providers and communities, so that community members might provide local organizations with information about individuals in need of services. During in-country site visits, field notes from four organizations noted the centrality of advocacy work in supporting pediatric post-surgical access to community-based care.

Specific outreach efforts included community-based education sessions about disability, trainings for health care workers regarding the unique needs of children after surgery (e.g., self-catheterization training and pressure sore prevention), campaigns to promote foster care and local adoption for children with post-surgical disabilities, and educational and sporting events for children with varying abilities.

A primary goal of "sensitization" includes the empowerment of communities to pass on their knowledge of surgical conditions and post-surgical recovery to other communities, potentially reaching more people than a single organization could on its own.

Table 5. Supports: most coded themes and sub-themes regarding barriers to service access in qualitative interviews and field notes.

Theme	Subtheme(s)	Percentage of participants that mentioned subtheme	Percentage of organizations with theme noted in field notes
Caregiver support	Accessible training and education	50% (n = 4)	50% (n = 4)
	Support groups	25% (n = 2)	37.5% (n = 3)
Awareness	"Sensitization"	50% (n = 4)	25% (n = 2)
	Advocacy	50% (n = 4)	50% (n = 4)
Sustained follow-up	Exercise and rehabilitation	50% (n = 4)	62.5% (n = 5)
	Nutrition	37.5% (n = 3)	37.5% (n = 3)

Bolded % not a primary barrier in field notes.

It would be good for organizational leaders to reach local community leaders to carry out sensitization about their available services and disability. – Participant 7, a Ugandan program director

Service providers will find a local leader who knows everyone in the community or follows the trail of whisperers to the child that has a disability. And then they'll work to do that first sensitization to say 'you shouldn't keep this child in hiding' and then move them to our group. – Participant 3, an American executive director

We reach out to responsible community members and tell them how we should love and care for these children. They help us to reach those ones who have not heard this. – Participant 6, a Ugandan parent of a child with disability and program director

Such sensitization can take multiple forms, ranging from in-person contact to various media outlets such as TV and radio.

Sensitization can be direct or indirect ... you can do it on the radio, you can do it on TV, you can do it in person. Awareness about conditions is something that really makes a lot of difference. – Participant 2, a Ugandan physiotherapist

Advocacy for children following surgery was also a prominent sub-theme for awareness-raising efforts. Four interviewees noted that it was of particular importance that individuals and groups within communities recognized and acted in the interest of children post-surgery, especially those with disabilities.

An inclusion community committee is important ... which is where all the local business, government, and religious leaders are united as advocates to set a strategic plan for their community on how to get their community more inclusive. – Participant 3, an American executive director

Collaborations came about mainly because of the Ugandans saying 'we have a problem in our community.' – Participant 4, a British program director

Half of the organizations that participated in site visits noted the importance of partnerships with private hospitals and other local organizations in order to more effectively provide pediatric follow-up services. The locus for these partnerships, per the field note data, is currently the Special Children's Trust in Uganda, a collection of over 50 Ugandan organizations that meet regularly to enhance distribution of resources to children with surgical conditions and disabilities.

Additionally, one interviewee emphasized the importance of advocacy and sensitization among service providers and organizations visiting Uganda for short-term medical missions, especially in relationship to follow-up care and community education.

Please don't just come in and do a surgery, but come in and spread awareness and understanding first. – Participant 3, an American executive director

Sustained follow-up care

Access to sustained follow-up care arose as a key support for pediatric post-surgical community reintegration among four interviewees and five site visit organizations. Follow-up care was understood as any kind of check-up care following surgery, such as return medical or therapy appointments. These "post-surgery" supports fell into two primary sub-themes: nutrition and exercise-based rehabilitation.

Three interview participants emphasized the key role of nutritional support in describing the supports best facilitating surgical recovery.

Nutrition is key...so that children don't deteriorate but keep on growing well. – Participant 6, a Ugandan parent of a child with disability; program director

Because they are all so poor they do not have very good nutrition and, obviously, they are all sick or disabled ... and therefore they

need a healthy diet. – Participant 8, a British physician and program director

We put them in a nutritional program to provide monthly supplements to their food so that they are getting proper nutrition. – Participant 5, an American chief executive officer

Field note data revealed that three distinct organizations supported their costs of operation by farming the surrounding land. This farming provided a source of fresh food for nutritional supplementation for the children participating in their community-based care, and also provided a means of selling goods to the larger community in order to cover surgical expenses.

Physical rehabilitation, especially programming related to exercise and assistive devices, also emerged as a central perceived support for children following surgery (four interviewees and five sets of field notes). This specific sub-theme focused on repeated training for caregivers and access to assistive devices in order to improve independence:

Even before they use the wheelchair, they should be trained. – Participant 6, a Ugandan parent of a child with disability; program director

Among the organizations where site visits were conducted, two organizations emphasized the importance of providing more outpatient services and caregiver training in order to increase capacity. This capacity building included training technicians to provide ongoing repairs to assistive devices. These two organizations also noted the importance of inter-organizational partnerships to allow for the distribution of assistive devices to children in more remote areas of Uganda.

Three interviewees also commented on the importance of physical rehabilitation, including caregiver directed exercises, in supporting recovery and community reintegration among children following surgery:

Ongoing therapy is an important thing that children have to do to get on their feet. – Participant 7, a Ugandan program director

A lot of children post-surgery need physio.– Participant 8, a British physician and program director

We train caregivers on how to do exercises and how to take care of their children. – Participant 6, a Ugandan parent of a child with disability; program director

Caregiver support

Although caregiver limitations were identified as a barrier in this study, caregivers also provide vital supports for children accessing community services following surgery. Four interviewees expressed that a caregiver's understanding and support make a critical difference in a child's post-surgical recovery and reintegration. Field note data from four distinct organizations also emphasized this specific support.

If you find a family that is very supportive of the child, you see a lot of differences.—Participant 2, a Ugandan physiotherapist

It really comes down to the parents. There's no one else who is going to actively work to reintegrate that child.—Participant 3, an American executive director

Some participants expressed that improvement of caregiver support could be achieved through support groups.

Parental support has been very, very positive in Mbarara. They have the best system of parental support. The parents are very, very cooperative. – Participant 2, a Ugandan physiotherapist

We are not the only ones with parent support groups. It is a model you see used around Uganda. I think they are incredibly helpful because you have a parent understand what to expect and you have other

parents encouraging that parent. – Participant 3, an American executive director

Other ways to increase caregiver support include training programs. Specifically, training and education may address misunderstanding of post-surgical recovery.

The caregivers think that after surgery, it is supposed to correct everything ... so, we have to discuss with these mothers. I have health education every week.—Participant 2, a Ugandan physiotherapist

Two interviewees noted that they engage caregivers in a one-on-one context in order to provide individualized education and address any particular misunderstandings of their child's condition.

We have to sit them down and then try to ... train them, teach them, tell them what their role is ... they are not supposed to abandon these kids.—Participant 2, a Ugandan physiotherapist

We begin to talk with them, encourage them, explain to them what disability is. This is not witchcraft. This is not a curse. This is not a problem. It is a sickness and this child has to be taken care of. We train them ... we do parenting and restoring hope for them together with their children.—Participant 6, a Ugandan parent of a child with disability; program director

Two interview participants expressed that greater availability of caregiver education would be particularly valuable in supporting post-surgical pediatric recovery.

I think that the guardians need to be told the significance of the surgery, why the child is having it, the recovery rate, what the child might need, like a special diet or whatever it might be when they come out of it.—Participant 8, a British physician; program director

The service that needs to increase in Uganda is raising awareness of children with disabilities. Educating parents. To get parents in a workshop, so that we can explain to them what a disability is. For those ones who have never even had anyone talk to them and tell them what happened to their child and how they should handle their child ... someone to encourage them ... someone to say you have to understand and accept because this is your own child.—Participant 6, a Ugandan parent of a child with disability; program director

Discussion

There is little documented evidence about follow-up care and community reintegration after pediatric surgery in Uganda, and in LMICs more broadly. This study provides unique qualitative data from a service delivery perspective about the barriers and supports for children recovering from surgery to promote reintegration into their home, school, and community contexts post-surgery. We identified four key barriers (discrimination, finance, geography, and caregiver limitations), and three key supports (awareness, sustained follow-up care, and caregiver support). These seven themes emerged across all four domains of community-based services, and among both Ugandan and non-Ugandan nationals. Analysis of field note data from site visits supported the findings of discrimination, finance, and geography as key barriers as well as sustained follow-up care as a key facilitator for access of community-based resources among school-aged children after surgery in Uganda.

Mulumba et al. [41] found that despite policy efforts, the right to health for people with disabilities, including many children recovering from surgery, is not yet adequately protected, promoted, and fulfilled in Uganda. Their findings suggest that forms of anti-disability discrimination in Uganda can affect a person's ability to access health services. In our study, interview participants and data from the field notes suggested that a lack of information regarding children with disabilities – leading to

discrimination – often prevented reintegration and diminished the right to healthcare for children post-surgery. Previously, Bannink et al. [42] suggested that among children with certain surgical conditions – spina bifida and hydrocephalus – negative attitudes act as barriers to community inclusion and reintegration. Specifically, negative attitudes and stigma often result in bullying and verbal abuse of children with disabilities by community members in Uganda [43,44]. Bannink et al. [42] suggest sensitization and early intervention in dissemination of knowledge can help combat this discrimination. Interviewees in this study also identified sensitization and increasing awareness as key strategies to improving community reintegration.

Discrimination is often manifested by caregivers, who may act as barriers or supports depending on their understanding of their child's condition, as well as their overall engagement in their child's recovery and reintegration. Although discrimination within the community is a barrier, the interview and field note data suggest that discrimination is amplified by a lack of understanding of post-surgical conditions among many caregivers. Previous studies have documented how support groups can help parents reduce disappointment and stress related to their child's disability [23,42]. Our study's data also identified support groups and parental education as major facilitators to community reintegration of their children post-surgery.

Finances and limited geographic proximity are observed barriers to care which negatively affect children seeking to reintegrate into the community following surgery. Ugandan households with individuals with disabilities often face poverty for an extended period of time [45]. Seven interview participants noted that financial and geographic barriers include a lack of transportation to centralized services. This specific barrier was also noted in five sets of field notes. An inability to afford post-surgical care services, assistive devices, and transportation are also key barriers for engaging in appropriate post-surgical care. A previous study that investigated the barriers to clubfoot treatment adherence in Uganda reported that treatment and transportation costs, coupled with poverty, hindered access to follow-up services [46].

The interview and field note data in our study identified sustained follow-up care as a major facilitator of community reintegration for the post-surgical pediatric population. Prioritizing the provision of community-based follow-up care presents a pressing consideration for clinicians and policy-makers in Uganda today. Creating sustainable and wide-reaching networks of follow-up care may further support recent findings that surgical care in LMICs helps protect families against further impoverishment [47]. Our study also supports the prioritization of transportation infrastructure to increase access to community-based rehabilitation centers among children residing in rural areas of Uganda [12].

While this study focused specifically on supports and barriers to recovery and reintegration among children who have undergone surgery, the data may also offer insights for supporting children with disabilities who do not have a co-occurring surgical condition. Like many children with disabilities, children requiring surgery often live with congenital or acquired deformities [12,20]. For example, a scoping review of the provision of rehabilitation services for children with disabilities in LMICs revealed similar personal, financial, and structural challenges in accessing the community-based services that we describe in this study [48]. Despite these similarities, it is important to note that children post-surgery face additional difficulties such as managing the transition from hospital to home, including referrals from tertiary to primary care. Children post-surgery also face an additional pressure to accessing community-based services to ensure sustained benefits of the

surgical intervention and to mitigate the risk of post-surgical complications [21,28].

Theoretical implications

This study's results provide data to support ongoing theorization and research regarding the ICF-CY's concern for "environmental factors:" those factors that "make up the physical, social and attitudinal environment in which people live and conduct their lives" [31]. Our study highlights the complexity of environmental factors, particularly in the way that they act as supports, barriers, or both, to pediatric post-surgical recovery and community reintegration. For example, though a caregiver might provide significant support to a child by enabling their consistent participation in a home exercise program, the same caregiver might also severely restrict a child's return to school and community activities due to cultural assumptions regarding disability.

In this way, our study theorizes that attention to the category of reintegration, which includes not only access to post-surgical community-based resources, but also meaningful participation in activities related to recovery across home, school, and community contexts, requires ongoing, interdisciplinary, and culturally responsive assessment of systematic factors related to children recovering from surgery in LMICs, and specifically in Uganda. The concept of "reintegration" is only mentioned once in the ICF-CY as "social integration" [31] – with concepts of access and functioning holding theoretical priority over the concept of integration or reintegration.

This study's findings theorize that environmental factors constantly and complexly influence pediatric post-surgical recovery and reintegration, not only as end goals, but as dynamic factors that directly influence service access and meaningful participation throughout the surgical recovery process. Therefore, we theorize that questions of access and participation must always be coupled with attention to ongoing processes of reintegration, especially how these processes relate to caregivers, economic and geographical issues, and cultural factors such as attitudes and assumptions. These systemic factors related to reintegration ought to be considered equally alongside important questions about service access. This theoretical shift to prioritizing consideration of environmental factors in processes of pediatric surgical recovery parallels recent shifts in global health, most notably, The Lancet Global Health Commission on High Quality Health Systems, which seeks to move away from questions of service access alone to investigate the layered factors that affect healthcare services, rooted in a commitment to culturally responsive care as a basic human right [49]. The results of our study theorize the importance of attending to the complex factors related to post-surgical care, especially as this part of the healthcare spectrum often receives less attention than primary care services and other public health initiatives such as vaccination and women's health.

Implications for services

The barriers and supports identified in this study reveal a number of gaps in service delivery that can be actionably addressed. Specifically, this study demonstrates the need for greater financial investment and capacity building of CBOs that work in pediatric post-surgical recovery management, including general pediatric organizations related to disability and rehabilitation. Although the current study's data suggest that some networks of individual organizations exist, we recommend increased attention toward strengthening strategic partnerships between medical centers,

non-government organizations (NGOs), as well as public and private services for supporting children transitioning back into the community after surgery. Our Ugandan collaborators emphasized the importance of developing a nationwide referral directory that maps all NGOs, CBOs, hospitals, and rehabilitation centers, so that children can be more efficiently referred to appropriate post-surgical services.

In addition, this study identified that caregiver support groups and training workshops were key facilitators for successful community reintegration. Further collaboration between existing organizations to share best practices – including the potential creation of clearly written instructions with simple illustrations regarding exercises, positioning, and potential warning signs of post-surgical complications – is a tangible avenue which our Ugandan collaborators identified as another needed resource for caregivers supporting children post-surgery.

One interview participant in our study indicated that their organization was able to sensitize the community to pediatric-specific disability through the development of an "inclusion committee." This model could be scaled to other parts of Uganda as well as other LMICs. Furthermore, our interviewees noted the logistical challenges of both affording and accessing rehabilitation services. Given that roughly 71% of the Ugandan population owns a mobile phone and 95% of the country's population has cellular network coverage, it is possible that mobile health (mHealth) interventions may promote and sustain pediatric post-surgical follow-up care, ultimately supporting optimal recovery and community reintegration [50]. One previous study in Uganda revealed how patients recovering from a stroke and their families were able to receive instructions for exercise and encouragement from therapists over the phone [51].

A final implication for services involves efforts to connect existing surgical centers (as well as intermittent surgical mission teams) to take on the burden of coordination with follow-up and community-based services for pediatric surgical patients. This implication involves ensuring that surgical interventions have an established pathway for referral to follow-up resources, accompanied by a focus on communicating typical recovery patterns, both in short- and long-term trajectories.

Implications for research

This exploratory case study provides novel insights into factors that support and restrict post-surgical pediatric recovery, factors often left under-investigated and poorly theorized in quantitative inquiries. Consistent with Charmaz's framework for a constructivist grounded theory approach, our study generated suggestive yet incomplete conclusions to inform future research [34,35]. Future studies within Uganda or other LMICs could further explore the perspectives of caregivers, of children themselves, as well as governmental officials. Gathering perspectives from a broader stakeholder group could further guide intervention development to improve access and greater participation in activities supporting recovery and reintegration. Our findings regarding cultural understandings of pediatric surgical conditions and disabilities suggest that culture is a significant determinant in poor post-surgical access to community-based services and overall recovery and reintegration. The pervasive influence of discrimination related to surgical conditions and disabilities among children in Uganda uncovered in our study calls for future interdisciplinary research, including sociological and anthropological analyses specifically related to cultural influences on post-surgical pediatric recovery and reintegration.

Outcomes research is needed on programs identified as facilitators to community-reintegration, such as parent support groups and inclusion committees, in order to inform scale-up. This study could also be replicated in other LMICs to begin to determine opportunities for translation across regions. Similarly, a multi-country comparison of post-surgical care and community reintegration could identify additional interventions for adoption and translation.

Limitations

Our study included perspectives from a small subset of individuals representing CBOs. Our study yielded a response rate of 53.8% ($n = 14$), consistent with a recent meta-analysis of response rates in qualitative research among health care providers [52]. While interview sampling size was small ($n = 9$), we undertook sampling and recruitment from a “maximum variation” approach [33,35], placing minimal restrictions on participants for study enrollment. In addition, our mixed-methods design of an exploratory case-study and modified grounded theory approach allowed for the gathering of data marked by “thick description” [33] instead of gathering more superficial data from a larger number of participants.

Unfortunately, the interview that was discarded due to technical issues represented an additional Ugandan participant. Its removal skewed the data further toward non-Ugandan interviewee perspectives. Interviews with multiple stakeholders from the same organization may have reduced individual bias in the data, though data in the present study did resonate across multiple organizational affiliations and found consistent overlap with the field note data analysis. In addition, although we aimed to focus interviews on children post-surgery, many participants often generalized their responses to children with disabilities, regardless of whether or not the child underwent surgical intervention.

Finally, this study mainly focused on the perspectives of professional and other staff from CBOs, although one participant was also a parent of a child with a disability. As a result, participants may have held biases toward identifying caregivers as barriers (rather than healthcare, organizational, and community-based staff members). Future studies should include additional perspectives from parents and adults who underwent surgery during their school-aged years, in order to both corroborate and expand the results of the present study.

Conclusions

This study provides new data on barriers and supports to community reintegration for children post-surgery. Despite the striking pediatric surgical need in Uganda and the importance of comprehensive post-operative care for successful recovery, little research has been conducted regarding access to and participation in community-based services. To our knowledge, we provide the only qualitative study that explores barriers and supports for community integration for children post-surgery in Uganda. Compared to surveys, qualitative interviews reveal more nuanced and candid perspectives not previously considered in the research literature [53,54]. This study concludes that central barriers faced by pediatric patients after surgery in Uganda include an inability to access or afford services, as well as limitations in caregiver capacity and discrimination rooted in cultural assumptions about surgical conditions and disability. However, this study also concludes that community-based services both facilitate and support reintegration by promoting awareness in the community, educating

caregivers, and improving access to sustained follow-up care. Future attention to and investment in these particular supports will help to mitigate the barriers that children face to meaningful participation in their home, school, and community contexts following surgery.

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