# **BMJ Open** Children and adolescents with physical disabilities: describing characteristics and disability-related needs in the Kilimanjaro region, north-eastern Tanzania – a cross-sectional survey

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#### ABSTRACT

**Objectives** To describe the characteristics and disabilityrelated needs of children and adolescents with physical disabilities in the Kilimanjaro region, North-Eastern Tanzania.

**Design** A cross-sectional community survey was conducted from November 2020 to June 2021. Trained research assistants interviewed primary children's carers using a questionnaire based on the International Classification of Functioning, Disability and Health-Children and Youth Framework. Data were analysed using IBM SPSS Statistics V.27. The Pearson  $\chi^2$  test was used to examine differences between age, gender and self-reported needs. The independent t-test assessed difference in needs according to age and gender.

Setting Kilimanjaro region, Tanzania.

**Participants** Children and adolescents, aged 2–18 years, with physical disabilities (n=212).

**Results** Almost 40% had severe speech (n=84) and joint mobility (n=79) impairments, and more than half (n=124) had severe or complete difficulties walking. In aspects of self-care (caring for body parts, toileting, dressing, eating and drinking), most had severe and complete difficulties. Almost 70% (n=135) of households were located near health facilities without rehabilitation services. About onequarter (n=51) had never received rehabilitation services. More than 90% (n=196) needed assistive devices, and therapeutic exercises (n=193). Over three-quarters needed nutritional supplements (n=162).

**Conclusion** Children and adolescents with physical disabilities in North-Eastern Tanzania have impaired speech and joint mobility, and difficulties in communication, self-care and walking. Rehabilitation services essential for addressing these impairments and activity limitations are either scarce or inaccessible. Action is needed to facilitate urban and rural access to rehabilitation services in order to improve the well-being of children and adolescents with physical disabilities.

#### BACKGROUND

In low-income and middle-income countries, disability is a neglected global health topic.<sup>1</sup> Globally, 240 million children with disabilities

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study provides insights into the needs of children and adolescents with physical disabilities in urban and rural parts of Tanzania.
- ⇒ Data were collected using a contextually relevant, pretested, validated questionnaire administered to primary children's carers.
- $\Rightarrow$  The COVID-19 pandemic impeded fieldwork in the Same, Mwanga and Siha districts.
- ⇒ It was not possible to attribute causation. The recall and reporting of information by some carers may have been imprecise.

have unmet needs and experience significant socioeconomic inequalities.<sup>2</sup> The majority live in sub-Saharan African countries where opportunities to access essential services are minimal.<sup>1–3</sup> In Tanzania, 2.3% of children have disabilities.<sup>4</sup> The UN Convention on the Rights of the Child defines childhood as the age from birth to 18 years; this construct overlaps with the WHO definition, which denotes adolescence between 10 and 19 years.<sup>56</sup>

The International Classification of Disability, Health and Functioning (ICF) defines disability as an umbrella term representing impairments covering bodily function, structural issues, activity limitations and problems related to task execution and participation restrictions, that is, constraints in life interactions.<sup>7</sup> The children and youth version of ICF (ICF-CY) provides a valuable conceptual Framework and a common language for documenting the characteristics of health and functioning in research and healthcare.78

Physical disabilities are impairments in body structures or functions affecting the individual's mobility and participation in

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**Figure 1** Illustration of the organisational structures in society and the structure of the healthcare system in Tanzania. Rehab, rehabilitation.

daily activities.<sup>9</sup> In children, physical disabilities may occur before birth (congenital) or can be acquired during, or after birth, due to injury and/or illnesses.<sup>10</sup> If not addressed, physical impairments lead to activity limitations and participation restrictions throughout life.

Children and adolescents in low-income settings often face prejudice and lack access to essential services.<sup>1 3</sup> Data on the prevalence and overall magnitude of physical disabilities in children are limited and this scarcity of knowledge is more severe in poorly resourced settings. In Malaysia and Kenya, 2.8 and 5 per 1000 children, respectively, are reported to have physical disabilities.<sup>10 11</sup> In 2008, a national survey in Tanzania estimated that there were 1.4 per 1000 physical disabilities in children aged 7–19 years.<sup>12</sup> Comparing disability statistics is complex because of differences in information capture and ways of measuring and reporting the metrics.<sup>3</sup>

Children with physical disabilities have a broad spectrum of contextual needs related to age and severity.<sup>1 3</sup> This study conceptualises needs resulting from impairments and activity limitations as being 'disability related'. Addressing the disability-related needs of children and adolescents with disabilities demands multisectoral efforts and long-term follow-up.<sup>113</sup>

In Tanzania, service provision to meet the needs of children is feasible within the country's administrative and healthcare system structure illustrated in figure 1.<sup>14</sup> The administrative structure of Tanzania comprises hamlets, villages, wards, districts and regions. Tanzania's mainland has 31 regions and 184 districts subdivided into wards, villages and hamlets being in rural areas, and streets in urban areas.<sup>15 16</sup> Health facilities proximal to communities include dispensaries in villages and health centres in wards and district hospitals.<sup>14</sup> The facilities within a district jurisdiction constitute primary healthcare.<sup>14</sup> Secondary healthcare facilities are the regional referral hospitals that exist countrywide. Tertiary facilities include zonal and consultant/specialised hospitals. Personnel for rehabilitation are scarce in primary healthcare facilities.<sup>17</sup> The role and function of rehabilitation in the Tanzanian healthcare system is undetermined.

A well-defined and formalised structure for rehabilitation services in Tanzanian healthcare is both necessary and overdue.<sup>18 19</sup> Tanzania ratified the international Convention on the Rights of Persons with Disabilities in 2007 and 2009.<sup>9 20</sup> The Tanzanian disability policies of 2004 and the Persons with Disabilities Act (2010) advocate upholding the physical, social and economic welfare of children with disabilities and their families.<sup>21 22</sup> However, irrespective of legislative commitments, services available to address the needs of children with disabilities are inadequate in Tanzania.<sup>23 24</sup>

There is a need for timely recognition of children with disabilities in Tanzania. Early identification followed by appropriate intervention may help reduce prevailing impairments and address activity limitations and participation restrictions for irreversible conditions. This can mitigate the impact of the disability on the individual and the family, especially in later life. Tanzania does not currently have a national programme for early intervention.<sup>18</sup> Early identification is a challenge in poorly resourced settings where the disclosure and identification of children with a disability is a sensitive issue.<sup>3 25 26</sup>

With regard to rehabilitation, WHO recommends a community-based rehabilitation (CBR) model in poorly resourced settings.<sup>27</sup> The CBR model empowers persons with disabilities and families to rehabilitate in their respective communities.<sup>28</sup> In Tanzania, the concept is not new. However, implementation has been poorly documented.<sup>23</sup>

In the Kilimanjaro region, CBR services for children are coordinated by non-government organisations (NGOs) in partnership with district health departments.<sup>29</sup> However, the accessibility of rehabilitation services is limited, especially in rural areas.<sup>26 30</sup> Describing the magnitude of disability-related needs is crucial for generating the evidence necessary to inform planners and stakeholders. Assessing the characteristic features of disability is also essential for generating knowledge to improve interventions. Characteristics, in the context of this study, resonate around features related to impairments (visual, hearing, speech/communication), mobility challenges, services and needs associated with individual children and families.

This study aims to describe the characteristics and disability-related needs of children and adolescents, aged 2–18 years, with physical disabilities in the Kilimanjaro region, and investigate gender and/or age differences in the reporting of disability-related needs by children's carers. The specific aims are to: first, describe characteristics such as social demographics, types of diagnoses and self-reported complications; second, describe impairments (visual, hearing, speech, joint mobility) and activity limitations (communication, mobility, washing, toileting,

dressing, eating, drinking), and third, describe the services available (nearby healthcare facilities, access to rehabilitation, possession of health insurance).

# **METHODS**

# Setting and study design

A cross-sectional community survey was conducted in Kilimanjaro from November 2020 to June 2021. Kilimanjaro is located in the foothills of Mount Kilimanjaro and has a population of more than 1.8 million.<sup>15 31 32</sup> A large proportion of the population lives in rural areas. The administrative structure of the region comprises districts/ municipalities, wards, hamlets and villages in rural areas, and streets in urban areas. The Kilimanjaro region constitutes one municipality and six district councils. Essential rehabilitation services for children with disabilities are scattered but mostly located in urban areas.

#### **Study population**

The study subjects were children and adolescents aged 2–18 years (n=212). The operational definition of 'physical disability' used here refers to any lifelong physical impairment with or without associated mental, cognitive or other impairments that interfere with functioning and participation in society with others.<sup>9</sup> Primary carers, aged 18 years and above, were the key informants. They are defined as family members (aged 18 and above) who had provided care and support to the child in all aspects of their life.<sup>33</sup> Children who presented with an acute medical condition were excluded and advised to visit a nearby health facility for possible treatment.



**Figure 2** Flow chart diagram delineating the sampling and recruitment procedures. District council (DC) district, a ward is a subdivision of a district; a village is a subdivision of a ward in rural areas or a street in urban areas. in rural areas, villages are further subdivided into Hamlets and Hamlets into ten cells (10 houses).

#### Sampling methods

The study involved three sampling stages, as illustrated in figure 2. The process employed a random selection of wards followed by a total sampling of villages and households. The wards were subdivided into villages in rural areas and streets in urban areas. On average, wards consisted of three villages or streets (ranging between two and six). In the first stage, the first author (EAS) listed all wards on equal-sized pieces of paper for each district.<sup>31</sup> The named pieces of paper were enclosed and mixed in a box (separately for each ward) by a person external to the study team. In the final step nine pieces of paper were randomly picked for each district. In the second and third stages, all villages/street and households of children with physical disabilities in the randomly selected wards were included.

In the Moshi municipality, the first drawn sample mainly comprised business premises, industrial areas, educational facilities and a railway. Accordingly, an additional sample of nine wards was drawn using the same procedure in order to enhance the representation of Moshi residents. There were fieldwork and data collection problems in the Same, Mwanga and Siha districts due to the COVID-19 pandemic.

#### **Data collection tool**

The data collection tool was a questionnaire based on the ICF-CY.<sup>7</sup> Questions were adapted from a local community survey questionnaire undertaken by the Institute of Public Health (IPH), Kilimanjaro Christian Medical University College.<sup>34</sup> This IPH tool had been previously peer-reviewed by experts in rehabilitation, public health and epidemiology and frequently applied in communities by undergraduate medical students.<sup>35</sup>

The variables for analysis covered sociodemographic information, complications and service profiles (access and availability) and were directly adopted from the questionnaire without modification. They were mainly nominal measurements, that is, 'yes/no' with a continuous scale for age expressed in years. Variables for impairments and activity limitations were captured on an ordinal scale ranging from '0: no impairment' to '4: complete impairment'. Allowing for linguistic issues the final fourpoint impairment scale (in Swahili) was: '0=no impairment', '1=some impairment', '2=severe impairment' and '3=complete impairment'. 'Mild and moderate' in the original scale was replaced by 'some impairment'. This scoring is in line with Washington Group Short Set on Functioning tool.<sup>36 37</sup> The word 'impairment' was replaced with 'difficulty' in the domains assessing activity limitations.

The ICF-CY was used in the study because validated tools for assessing disability characteristics are scarce. As well as being generic and offering a comprehensive opportunity to describe disability characteristics,<sup>7</sup> the framework offers a unified language for assessing problems manifested in childhood and adolescence concerning functions and structures of the body and activity limitations.<sup>7</sup> For consistency with study aims, the impairment and activity limitation domains were included.

The final tool used here was informed by a review of the literature reporting on evaluations of children with disabilities and their family needs.<sup>37–39</sup> In its draft phase, the tool was pretested among children receiving care at a CBR facility in the Moshi municipality. Content validity was checked by two physiotherapists and two occupational therapists with expertise in child rehabilitation. Reported priority needs comprised eight categories (assistive devices, therapeutic exercises, nutritional supplements, special education, regular hospital visits, medication, use of sign language and surgery). Coding was binary, that is, a reported need (1) or no reported need (0). An open-ended option, 'other needs', was included to allow respondents to provide information about other needs outside the defined categories. The questions were translated into Swahili by two language experts (one Swahili teacher from a local university and another from a secondary school) and the first (EAS), second (SEM) and third (HM) authors.

underwent pretesting once, The questionnaire involving 24 carers of children with disabilities aged 2-18 years. A pilot study was carried out to assess the practicality of the tool before the actual data collection. The final questionnaire comprised three sections with the first capturing carers' profiles, and the second and third sections capturing information about the children. The second section included subsections labelled part (A) for basic information, (B) for health and services and (C) for impairments and activity limitations. Two research assistants (physiotherapists) assessed the reported diagnoses by observing the child or adolescent as they played or attempted to perform activities. Data from the pilot study are not included in this analysis.

#### **Data collection**

SurveyCTO software was used to collect the data electronically using a Samsung Galaxy Tablet Version Two. SurveyCTO offers additional advantages in designing, monitoring and archiving data compared with a traditional paper-based questionnaire. The software ensures data security through end-to-end encryption.<sup>40</sup>

Data collection involved two field research assistants (newly graduated physiotherapists) who underwent rigorous pretraining on study protocol and tools. The data collection team comprised the two research assistants and the first author (EAS). The ward executive officers provided the research team with the first link to the community, including the names and contact numbers of the village and sub-village leaders. Before fieldwork, the village leaders made a list of all households known to have children/adolescents with disability between and including the ages of 2–18 years. The data collection team met with village leaders who linked them to individual households.

The questionnaire was administered in face-to-face interviews because some carers had low literacy. The

interviewer read each of the questions word-for-word and recorded responses. Where there were open-ended options, the responses were registered as enunciated by the informants. On average, the interviews were of 30 min duration. They were held in the households. The data collection team held daily debriefings and refreshed the protocols every second day of data collection to minimise interviewer bias. The first author (EAS) checked all submitted questionnaires daily for completeness and accuracy. To ensure data quality, the first author (EAS) also performed a daily random check of response patterns, time per interview and the Geographical Information System number.

#### **Data analysis**

The first author (EAS) imported a data file from the SurveyCTO server. IBM SPSS V.27 was used to process and analyse the data. Most variables were categorical. The option 'not applicable' was labelled as 'missing'. Age reported in years was categorised according to the WHO definition of children and adolescents. Counts and proportions were used to summarise the nominal and ordinal variables. Age and gender differences in reported needs are given using the Pearson  $\chi^2$  test. If the number of participants for a specific category was small, Fisher's exact test was used. Means testing using independent t-tests assessed the difference in reported needs per child according to age and gender.

#### Patient and public involvement

During the questionnaire design, pretest and piloting, carers of children with disability and experts in paediatric rehabilitation (physiotherapists and occupational therapists) were involved. District executives gave permission for the conduct of the study. The findings will be disseminated through open-access publications.

#### RESULTS

Table 1 shows the demographic and disability-related characteristics of the 212 children with physical disabilities who were enrolled in the study. There were 60 children aged under 5 years and 72 aged 5–9 years. Just over one third (n=80) were adolescents. During infancy, respiratory infection, meningitis and malaria were the most prevalent conditions (n=116). Commonly reported complications were joint contractures (n=93) and spasticity (n=97). Two thirds had cerebral palsy (n=142). In some, the condition coexisted with other diagnoses (n=27). Three-quarters (n=158) of the carers were mothers, and the majority were aged between 25 and 54 years. Just under half were married (n=102), and the majority (n=156) had attained at least formal primary education.

Table 2 shows the availability of health services. Most households with a disabled child (56%) lived close to dispensaries (the lowest primary healthcare facility); 77% were not covered by a health insurance scheme. Rehabilitation services were not available at the nearest

Table 1	Characteristics of children and adolescents with
physical	disabilities and their carers in the Kilimanjaro, north-
eastern 7	Tanzania (n=212)

Variables	Subcategories	n (%)					
Children and adolescent characteristics							
Sex	Male	103 (48.6)					
	Female	109 (51.4)					
Age (years)	Children (2–4)	60 (28.3)					
	Children (5–9)	72 (34.0)					
	Adolescents (10–18)	80 (37.7)					
Area of	Rural	127 (59.9)					
residence	Urban	85 (40.1)					
Onset	Born with (congenital)	102 (48.0)					
	Developed later in life (acquired)	110 (52.0)					
Illnesses (first	Infections*	116 (54.7)					
12 months)	Jaundice/high fever	46 (22.7)					
	Epilepsy	45 (21.2)					
	Vomiting and diarrhoea	18 (8.5)					
	Trauma	11 (5.2)					
	Other	10 (4.7)					
Reported	Convulsions	56 (26.4)					
complications	Spasticity	97 (45.8)					
	Contractures	93 (43.9)					
	Incontinence	76 (35.8)					
	Pressure ulcers	22 (10.4)					
	Other	18 (8.5)					
Diagnosis	Cerebral palsy	142 (67.0)					
	Cerebral palsy and other (mixed)	27 (12.7)					
	Hydrocephalus and spina bifida	10 (4.7)					
	Muscular dystrophy	12 (5.7)					
	Skeletal malformations	9 (4.2)					
	Other†	12 (5.7)					
Carers character	istics						
Sex	Male	18 (8.5)					
	Female	194 (91.5)					
Age (years)	Early working age (≤24)	17 (8.0)					
	Prime working age (25-54)	166 (78.3)					
	Mature working age (55–64)	20 (9.4)					
	Elderly (≥65)	9 (4.2)					
Relationship	Mother	158 (74.6)					
	Grandparent	31 (14.6)					
	Father	14 (6.6)					
	Other	9 (4.2)					
		Continued					

Table 1 Continued						
Variables	Subcategories	n (%)				
Education	Never went to school	13 (6.1)				
level	Primary education	156 (73.6)				
	Secondary education	37 (17.5)				
	College/university education	6 (2.8)				
Marital status	Married	102 (48.1)				
	Not married	110 (51.9)				

\*Infection—respiratory, malaria and meningitis infections. †Other—Down syndrome, amputation, rabies, head trauma and spinal cord injury.

health facilities for more than two-thirds (n=135); almost a quarter had never used rehabilitation services (n=51).

Online supplemental figure 1 shows almost 40% of children had severe speech impediments and more than a third had severe joint mobility impairments. Figure 3 shows activity limitations in the domains of communication (A), mobility (B) and self-care (C). Nearly half reported severe-to-complete difficulties in producing

Table 2Health services for children and adolescentswith physical disabilities in the Kilimanjaro, north-easternTanzania

Variables	Frequency	%	
Nearest health facility			
Dispensary (healthcare facility within villages)	119	56.1	
Health centre (healthcare facility within wards)	32	15.1	
Hospital*	61	28.8	
Rehabilitation services in the nearest facility (n=194)			
No	135	69.6	
Yes	59	30.4	
A child covered by health insurance			
No	164	77.4	
Yes	48	22.6	
Type of insurance (n=48)			
Community health fund	10	20.8	
National health insurance fund	38	79.2	
Rehabilitation services in past month			
No (has never had any before)	51	24.1	
No (had used before and stopped)	84	39.6	
Yes	77	36.3	
Type of rehabilitation (n=77)			
Community-based	11	14.3	
Institutional	66	85.7	
*District hospital, regional hospital, tertiary hospital or private			

\*District hospital, regional hospital, tertiary hospital or private hospital.

#### **Open access**



Figure 3 (A) Activity limitations in the communication domain. (B) Activity limitations in the mobility domain. (C) Activity limitations in the self-care domain. Children aged 2-4 years are not included in self-care damain.

(sending) verbal information. More than 40% had severeto-complete difficulties with non-verbal communication. The majority (59%) had severe-to-complete difficulties in walking. In the self-care domain, more than half had severe-to-complete limitations in all subdomains.

Figure 4 shows the disability-related needs of children and adolescents. The average reported needs per child were 5 (±1.6). Figure 4A shows the statistical mean difference in reported needs according to age. Assistive devices (93%), exercise therapy (91%) and nutritional supplements (76%) were the most commonly reported needs, as seen in figure 4C. Figure 4E also shows a significant association between age and reported need for assistive devices: (n=127), p=0.013; therapeutic devices: (n=125), p=0.017; nutritional supplements: (n=111), p=0.001; regular hospital visits: (n=79), p=0.014 and medication: (n=71), p=0.034. Needs were more likely to be reported for children rather than adolescents. The association between reported needs and gender was not statistically significant.

ercent p=0.571 40 20 Regular Nutritional Special Use of Sign Assistice Therapeutic Hospital Medication Surgery Devices Exericses Supplements Education Language Visits 52 31 Male 90 68 82 56 54 Eemale 93 92 50 28 5 120 p=0.013 p=0.001 100 80 p=0.014 p=0.034 60 Percent 40 p=0.260 20 Therapeutic Nutritional Special Education Regular Hospital Use of Sign Assistice Medication Surger Devices Exericses Supplements Language Visits Children 95 84 58 60 54 32 Adolescents 86 85 64 69 53 39 25 Figure 4 (A) Mean number of reported needs according to age; (B) mean number of reported needs according to gender; (C) the categories of disability-related needs; (D) distribution of the reported disability-related needs according to sex; (E) distribution of the reported disabilityrelated needs according to age.

### DISCUSSION

А

Age group

Adolescent

Childr

100 с 80

60

40

20

Percent

100

80

D 120 Assistive

device:

92 5

2

91

p=0.812

Research on the needs of children with disabilities in Tanzania is scarce. This study sheds light on the characteristics and needs of children and adolescents with physical disabilities in the Kilimanjaro region of Tanzania from a medical rehabilitation perspective. The majority of children and adolescents in the study had acquired their disabilities after birth. Potential risk factors for disability include poor perinatal services, infections and non-communicable diseases.<sup>41 42</sup> Carers reported infections (malaria and meningitis) and jaundice during the first twelve months of the children's lives. Better knowledge of associations between early childhood illnesses and disability requires further investigation to inform strategies for prevention.

Consistent with other research43 44 cerebral palsy was the most common reported childhood diagnosis in this study. Cerebral palsy is a syndrome accompanied by

в t=3.528 (p=0.001) Sex 1 4 ł 16 12 4 Mean No. of reported needs Mean No. of reported needs Regular hospita Nutritional supplements Special Educatior Use of sigr language Therapeutic Medication Surgery visits 76.4 61.8 48.1 29.2 42 533 p=0.67 =0.072

6

t=-0.185 (p=0.853)



The age group difference suggests that disability increases with age, a finding supported by a UNICEF situation analysis and the Tanzania 2008 Disability Survey.<sup>4 12</sup> Substantial progress has been made in reducing infant mortality, particularly in low-income and middle-income countries.<sup>47–49</sup> Infants and children are living longer but not necessarily disability-free; more resources are needed to help the growing numbers of children with disability needs. In sub-Saharan African countries, the numbers of children and adolescents with disabilities are increasing yet there are fewer resources and services.<sup>18</sup> As noted by Cieza *et al*,<sup>113</sup> there is an urgent need to integrate disability as a priority in the global health agenda.

A significant number of children in this study had no health insurance. Rehabilitation services are lacking in primary healthcare. District and regional referral and consultant hospitals offer rehabilitation services but they are generally distant from rural areas. This may explain why nearly a quarter of the carers reported that their children had never received any rehabilitation service. They commonly reported joint mobility impairments, complications and difficulties in self-care that are worsened due to lack of access to services. These findings align with other studies in low-and middle-income countries where the scarcity or lack of rehabilitation services is evident.<sup>23</sup> 25 30 35

The lack of available personnel for rehabilitation is reflected in the revised 2014–2019 staffing levels for health facilities under the Tanzanian Ministry of Health and Social Welfare.<sup>17</sup> Most primary healthcare facilities have no allocated personnel for rehabilitation. At the district level, there are only a few physiotherapists and occupational therapists. A similar inadequacy is reported in other parts of sub-Saharan Africa.<sup>25</sup> The lack of nearby or accessible services deters people from seeking help and care. Increasing the capacity for rehabilitation in health facilities would be an important step.<sup>18 35</sup>

The need for CBR is well known.<sup>27</sup> Both the Disability Policy of 2004 and the Disability Act of 2010 support the realisation of CBR.<sup>21 22</sup> Currently, CBR services are limited and coordinated by NGOs in the Kilimanjaro region.<sup>29</sup> The sustainability of CBR services is uncertain. We recommend strengthening public–private partnerships to replicate the model implemented by these NGOs. Investment in rehabilitation personnel is a crucial and necessary step for achieving adequate staffing levels for CBR in primary healthcare facilities.<sup>18</sup>

Carers commonly reported impaired speech which can lead to severe and complete communication difficulties. Speech and language rehabilitation is rare in the region; children and adolescents with speech special needs are left without proper rehabilitation options.<sup>50</sup> The healthcare structure of Tanzania has no allocated personnel for speech and language rehabilitation.<sup>17</sup> Training and employment schemes for speech therapists are nonexistent. The unmet demand for speech rehabilitation is indisputable and is projected to increase unless services are introduced.

Assistive devices, exercise therapy and supplements were the most commonly reported needs. Similar findings have been shown in Thailand, where most children with physical disabilities need assistive devices for mobility and communication.<sup>51</sup> These assistive devices are fundamental for helping with mobility, functioning, independence and inclusion in society. However, assistive devices must be used with appropriate therapies. The findings of this study demonstrate that disability should involve interdisciplinary interventions, including nutritional support.<sup>18</sup> Similar results have been found in other studies.<sup>52</sup>

This work is an important start but more research, both quantitative and qualitative, is urgently needed. Important areas for investigation include the educational schooling of children and adolescents with disabilities, as well as access to services and support networks for children and families.<sup>53 54</sup> The COVID-19 pandemic highlighted these and other gaps.

One of the study strengths was the use of a contextually relevant, pre-tested, validated questionnaire administered to primary children's carers. The study benefited from having Tanzanian members of the research team who had local knowledge, understood cultural practices and sensitivities, and were fluent in the Swahili language.

There are also limitations. It was not possible to attribute causation to the associations due to the crosssectional study design. The authors acknowledge the possibility of recall and reporting bias. They also acknowledge that the representativeness of the data may have been compromised by the COVID-19 pandemic which interrupted data collection in the Same, Mwanga and Siha districts. The study focused only on children and adolescents with physical disabilities, and this limits the generalisability of the findings to children with mental and cognitive disabilities. The authors also acknowledge the possibility that the definition of 'disability-related needs' may have been misunderstood by some during recruitment.

# CONCLUSION

This survey is one of the few to describe the characteristics of physical disabilities in children and adolescents in Tanzania. Reported disability-related needs include exercise therapy, assistive devices and nutritional supplements. Rehabilitation services are not accessible to all in need and more research is needed to unpick demand and supply factors associated with access to rehabilitation services. We recommend revising the healthcare structure in Tanzania to include rehabilitation services at the primary health level and further empowering CBR programmes. Efforts need to be directed towards mobilising human resources and equipment to deliver locally accessible services.

# **Open access**

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**Contributors** EAS initiated, designed the study, collected, analysed and interpreted the data, wrote the article and revised the final version and is responsible for the data managment. SEM, HM, AS and ML equally contributed to the study design, data interpretation and revised the article's final version. K-GS oversaw the design of the study, interpreted the data and revised the final version.

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#### Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

#### Patient consent for publication Not applicable.

**Ethics approval** The study obtained ethical approval No. 2477 by the Kilimanjaro Christian Medical University Research Ethics and Review Committee. Participants gave informed consent to participate in the study before taking part.

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Data availability statement Data are available on reasonable request. The supporting data for this study are available on reasonable request. Data can be accessed online at https://disabilitybase.surveycto.com/main.html#Export.

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