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BEING YOUNG AND PHYSICALLY IMPAIRED

Voicing the needs and challenges of children, adolescents and their carers in Northeastern Tanzania

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Abstract

Background: Disability is a complex issue, yet it is often forgotten in development, and research agendas. The global disability agenda has gained significant attention over the past decade, particularly with its inclusion in the 2030 sustainable development goals that were adopted by all United Nations members in 2015. These goals are intended to promote inclusion and equal opportunities for all. Young people with physical disabilities face considerable barriers to participation in society due to negative societal norms, discrimination, and stigma, making them some of the most marginalised individuals in society. Existing laws are intended to support young people with disabilities in Tanzania, but implementation of these is lagging and remains limited. In Tanzania, 13% of families have a member with a disability, presenting unique challenges for all family members. Young people with physical disabilities are underrepresented in research, and there is a significant gap in public-health knowledge regarding this population. Research focusing on the needs of and challenges faced by the families and carers of these individuals is scarce, as is documentation on the societal inclusion of adolescents and young adults with disabilities in Tanzania. Understanding the disability-related needs and broader challenges faced by children, adolescents, and young adults with disabilities – along with their families and carers – is crucial for driving improvements in policy and practice.

Aim: This thesis aims to describe and explore the needs and challenges associated with being young and having a physical disability drawing on the perspectives of children, adolescents, and young adults with disabilities – along with their families and carers – in northeastern Tanzania.

Methods: The research was conducted in the Kilimanjaro region of northeastern Tanzania, using both qualitative and quantitative methods. A quantitative survey was completed by the primary carers (aged 18 years or older) of 212 children and adolescents with physical disabilities, aged between 2 and 18 years. The data collected during the survey were analysed in Studies I and III. The SurveyCTO software was used to collect data electronically via a questionnaire. The questionnaire was developed based on the International Classification of Functioning, Disability, and Health (ICF) framework. Statistical analysis (Studies I and III) was performed using IBM SPSS version 28. For the qualitative aspect of the research, Study II employed constructivist grounded theory, while Study IV analysed the experiences of adolescents and young adults regarding inclusion using reflexive thematic analysis.

Results: The findings of the quantitative study show that the children and adolescents with physical disabilities have significant difficulties with walking and self-care. Most of the participants described the adolescents/young adults in their care experiencing difficulties with social activities, household chores, and schooling, and reported needing assistive devices, therapeutic exercises, and nutritional support. Regarding essential services, most families lived near health facilities that did not provide rehabilitation services. Furthermore, a quarter of the children and adolescents with physical disabilities had never received any rehabilitation service. More than two thirds did not have health insurance. The carers faced psychological challenges, with over half of the 212 carers surveyed reporting poor psychological wellbeing, and 42% and 38% describing symptoms of anxiety and depression, respectively. Poor psychological wellbeing was significantly associated with symptoms of anxiety and depression; contrastingly, support from extended family members was linked to better psychological wellbeing and a lower likelihood of experiencing anxiety and depression. Various coping mechanisms were described by the participants, including avoidance, accepting their reality, and seeking alternative solutions in order to manage the challenges that they face. Support systems, particularly via social networks, were crucial in helping families meet basic needs and ensure the safety of their children. The adolescents and young adults, however, reported feeling marginalised, facing significant barriers to full societal integration, and experiencing an uncertain future with little hope.

Conclusion: This thesis found significant activity limitations among children and adolescents with physical disabilities in areas such as walking, self-care, communication, and participation in social activities, household chores, and schooling. Access to essential services, particularly healthcare, is inadequate, or in many cases impossible to access. Adolescents and young adults face both present and future barriers to full inclusion in society, and families are constantly adapting to meet the challenging needs of their children, with carers experiencing a considerable psychological burden. To address these challenges, it is crucial for the Ministry of Health to strengthen rehabilitation services within primary healthcare settings. Health-insurance reforms are also necessary to ensure the societal inclusion of young people with disabilities. Public-awareness campaigns that highlight the potential of people with disabilities and promote inclusivity are crucial for supporting social networks and challenging negative societal norms. Additionally, more investment is needed beyond policy statements, particularly in areas such as inclusive transportation, education, and public services.

Keywords: physical disability, adolescents, young adults, challenges, disability-related needs, rehabilitation, carers, Tanzania, Kilimanjaro region

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