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Research Article

ADDRESSING HEALTH DISPARITIES AMONG CHILDREN AND ADOLESCENT LIVING WITH DISABILITIES IN RWANDA-INSIGHT FROM SUCCESS

[1,2] * Norbert Dukuze, [1,2]Boniface Nsengiyumva, [2]Mathieu Ahishakiye, [2]Mariette Uwabikiramariya, [2]Hesron Twagirumukiza, [2]Frederic Tuyisenge, [3]Janine Frönd, [2,5]Gallican Kubwimana, [2,5]Laetitia Umulisa, [2,5]Harolimana Paul, [2,5]Pascal Uwimana, [2]Nsanzimana Sylvestre, [2,5]Benjamin Muhoza, [2,5,6]Lydia Businge, [2]Emmanuel Kagambirwa, [1,2,4,5]Leon Mutesa

[1]University of Rwanda, College of Medicine and Health Sciences, Centre for Human Genetics.
[2]Research for Development Rwanda
[3]1000 Hügel e.V
[4]Rwanda military Hospital
[5]Enstein foundation
[6]Rwanda Biomedical centre

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ABSTRACT

Children and adolescent living with disabilities face different health challenges depending on the type of restriction such as cognitive or mobility and the underlying condition, they often suffer health disparities in healthcare, there is a difference in persons with disabilities regarding to health outcome. Globally, there are more than 1.3 billion people with disabilities and the high percentage is children. The number of people in global south living with disability is about 80 millions out of which 10%−15% are children of school age. The causes of disability among children include congenital anomalies like genetic disorders or acquired conditions like epilepsy, vision loss, or hearing loss, cerebral palsy, poliomyelitis, tetanus, meningitis and malaria. However, these causes of disability are preventable and can be managed with early interventions and community rehabilitation services. The aim of this paper is to share the experience from mobile clinic approach in mitigating health challenges among children and adolescents living with disabilities and propose community rehabilitation as the main approach in reducing unnecessary suffering and address health disparities faced by children and families affected by disabilities. The mobile clinic carried out routine assessment of children with disability, training community health workers to provide education on disability and strategies for disability prevention to parents and caregivers, community rehabilitation like physiotherapy, orthopaedic surgery, hearing aid and family counselling to the community with the main objectives of promptly preventing and managing disability among children. Moreover, establishing these facilities requires shared commitment and multisector involvement and a synthesis of the global evidence is paramount to identify the factors that hinder equitable access to healthcare services for children with disabilities **Objectives:** To describe the characteristics and disability-related health needs of children and adolescents with disabilities in Karongi district, Western Province Rwanda. **Study Design:** A cross-sectional survey was conducted from June 2023 to October 2023. Trained research assistants together with mobile medical team interviewed door to door primarily children and adolescents living with disabilities, key informants and focussed group discussion for the qualitative part, children's carers were assessed using questionnaire based on World Health Organisation Disabilities Assessment Score(WHODAS 2), Multidimensional scale of perceived social support(MSPSS). Data were analysed using IBM SPSS Statistics V.27. **Study Setting:** Karongi District Western province-Rwanda. **Participants:** Children and adolescents, aged 0–17 years living with disabilities (n=400). **Results:** The present sample comprised of 230 (57.64%) male and 169 (42.36%) female with the mean age of 9 and (SD = 4.9) years. Almost 43.36%) demonstrated high social support, 43.07% and 13.57% reported medium and low social support respectively. **Conclusion:** Children and adolescents with disabilities in Karongi district western Rwanda have impaired speech, hearing impairment, intellectual disabilities, joint mobility, and difficulties in communication, self-care and walking. Community Rehabilitation, counselling services, financial support from different key partners are essential to address these impairments. It is therefore a responsibility to every member of the society to dismantle the ableism faced by children and adolescent with disabilities.

Keywords: health disparities, children with disabilities, social determinants of health.

INTRODUCTION

Background:

Children with disabilities make up around 150 million of the billion people with disabilities in the world. The Sub-Saharan African countries have a large number of children with disabilities who have limited access to healthcare and rehabilitation services [1]. different conditions like chronic poverty, low education, and low number patients to healthcare personnel substantially lowers these children's quality of life. The countries of sub-saharan Africa are home to many children with disabilities, many of whom lack access to basic healthcare services, The foremost cause of disability in Africa is infectious and communicable diseases [2]. The convention on the rights of persons with disabilitiesdefines living with a disability as having a long-term physical, mental, intellectual or sensory impairment that in interaction with the environment hinders one's participation in society on an equal basis with others. The United Nations Convention on the Rights of the Child places great importance on the rights of all children for the opportunities for survival, growth, health, and development [3]. The term disability' refers to any restriction or lack of ability to perform activities in the range considered normal for a human being.Multiple factors play a pivotal role in the development of disabilities in children and adolescents, these conditions manifest during early childhood and can have a lifelong impact on children, their families and communities.These conditions encompass acquired conditions like

***Corresponding Author: Norbert Dukuze,**
1University of Rwanda, College of Medicine and Health Sciences, Centre for Human Genetics,
2Research for Development Rwanda.

physical trauma,cerebral palsy while others can be congenital like intellectual and learning impairments, epilepsy, hearing and vision impairment, autism spectrum disorder and attention deficit hyperactivity disorder [4]. The healthcare research community increasingly recognizes the need to address social and environmental determinants of health to optimize access to healthcare for children and adolescent with disabilities. it is particularly relevant to disability and functioning and to those with childhood onset conditions that impair mobility and impact functioning and participation [5]. Persons with disabilities experience worse health outcomes when compared to the rest of the population in terms of premature mortality, increased morbidity, and limitations in functioning [6]. Social determinants of health are the complex circumstances in which individuals are born and live that impact their health. They include intangible factors such as political, socioeconomic, and cultural constructs, as well as place-based conditions including accessible healthcare and education systems, safe environmental conditions, well-designed neighborhoods, and availability of healthy food [7]. The social determinants of health play a critical role in inequitable access of healthcare services for persons with disabilities [8]. Most notably conditions like poverty experienced by persons with disabilities, often exacerbated by unemployment or homelessness, can limit care-seeking behaviours [9]. persons with disabilities are significantly more likely to live in poverty,under precarious housing conditions and have lower levels of education and employment than their non-disabled counterparts [10]. Children with disability are more at risk of stigma, many of the infrastructures, schools,hospitals are not equipped to meet their unique educational and health needs. Children from low-income families are more likely to live in neighborhoods with more environmental hazards, which may exacerbate rates of injury and exposure to traumatic events. Children with disabilities are more likely to experience food insecurity, parental depression and other mental health disorders [11]. health equity is attained wwhen everyone gets the chance to live as healthy as possible, Variations in life expectancy, quality of life, sickness, disability, mortality rates, disease severity, and treatment accessibility are all indicators of health disparities. A growing body of literature indicates that children,adolescent with disabilities and their families are more prone to experience economic disadvantage, most commonly in low- and middle-income countries [12]. The International Classification of Disability, Health and Functioning 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.In low-income and middle-income countries, disability is a neglected global health topic [13]. Adolescence can be defined as the ages between10 to 19 during which a person transitions from childhood to maturity, at this stage human body undergo different changes including biological, psychological, and social ones [14]. preventable differences in the burden, disease, injury, violenceor in opportunities to achieve optimal health experienced by socially disadvantaged racial, ethnic, and other population groups and communities are defined as health disparities [15]. Compared to children born in other regions of the world, African-born children are at higher risk for poor health outcomes. Such a child has a more than 50% likelihood of being malnourished and a high chance getting HIV at birth, whereas 51% of deaths are caused by acute respiratory infections, malaria, and diarrheal diseases [16]. Epidemiological data on childhood disability are lacking in Low- and Middle-Income countries, hampering effective service planning and advocacy [17]. referring to the 2019-20 Rwanda Demographic and Health survey The proportion of household members who have a lot of difficulty or cannot function at all in at least one domain increases from 2% among those age 5-9 and 4% among those age 30-39 to 32% among those age 60 and above.

Objectives:

the study was conducted to determine health needs of children and adolescent living with disabilities,Support health services at local Authority in Karongi district to create a database for children and adolescents with disabilities, assess disability-related health, psychosocial, economic conditions and health needs of Children with Disabilities and facilitate appropriate support.

PATIENTS AND METHODS:

A mixed-methods, sequential explanatory study design was used to collect and analyse quantitative (n = 400) and qualitative (n = 30) data from children, adolescents, parents to children and adolescents with disabilities in Karongi district, western province Rwanda. Quantitative data were analysed using descriptive and inferential statistics while qualitative data was analysed thematically. A cross-sectional survey was conducted from June 2023 to October 2023 both trained research assistants and community healthcare workers interviewed door to door primarily children and adolescents with disability. Karongi is one of the seven districts of western province-Rwanda. The district extends over an area of 993 km2 with total population of 331, 808 distributed into 77000 households. it is further divided into 13 administrative sectors and 88 cell.through Bienfait Mobile Health program, a team of general practioner, psychiatric nurse, orthopaedic technician and physiotherapist through operating as mobile clinics improved access to health care in many sectors of Karongi communities by reducing geographical barriers and financial resources. It was often the only available option for patients in areas with limited medical infrastructure, and resources. The program has substantially increased most of the primary care services, disease prevention through health education, health promotion, case management, and information and referral.

Study population:

The study participants were children and adolescents aged 0–17 years (n=400). The used definition of 'disability' here refers to a long-term physical, mental, intellectual or sensory impairment that in interaction with the environment hinders one's participation in society on an equal basis with others. 27 Primary careers aged 18 years and above and 3 local administrative leaders were the key informants. People above 17 years old were excluded from the study.

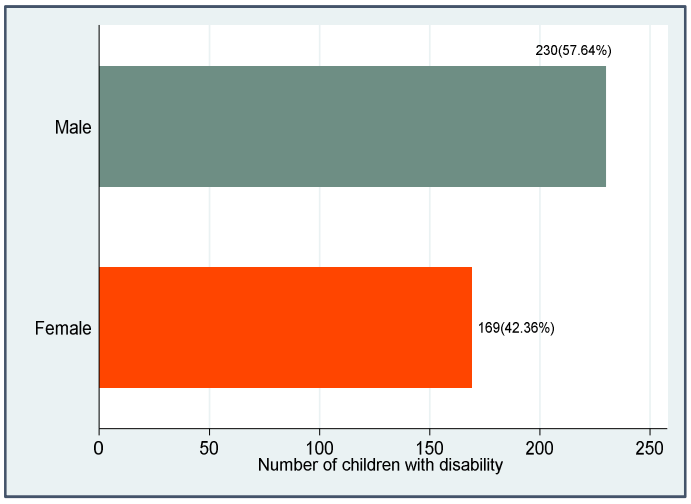
Sampling methods:

it requires application of the fine art and science of medicine to know what disease condition a patient has, mobile team of multidisciplinary healthcare providers and community health workers after intensive training employed door to door campaign. A cross-sectional community survey was conducted from June 2023 to October 2023. Trained research assistants interviewed primarily children and adolescents, key informants and focussed group discussion for the qualitative part, children's carers were assessed using a questionnaire based on World Health Organisation Disabilities Assessment Score (WHODAS 2) and multidimensional scale of

perceived social support(MSPSS). Data were analysed using advanced statistical software IBM SPSS Statistics V.27.

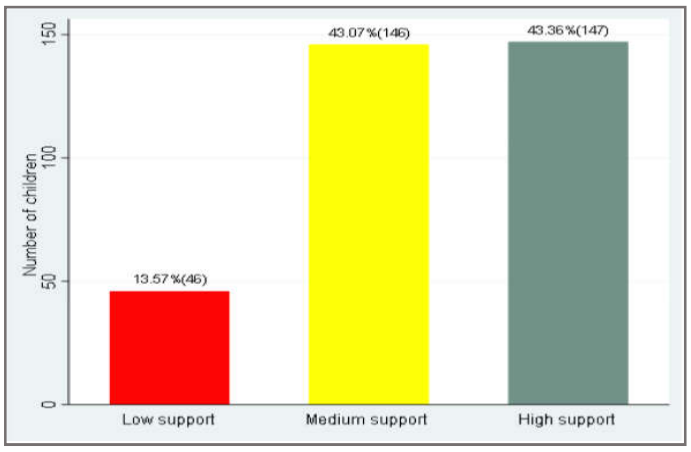
RESULTS

The present sample comprised of 230 (57.64%) male and 169 (42.36%) female with the mean age of 9 and (SD = 4.9) years. Almost 43.36%) demonstrated high social support, 43.07% medium support and 13.57% reported low social support respectively.



Multidimensional Scale of Perceived Social Support (MSPSS)

The Figure 2 reveals three levels of support: Low Support, comprising 46 instances (13.57%); Medium Support, consisting of 146 instances (43.07%), with a cumulative percentage reaching 56.64%; and High Support, with 147 instances (43.36%), contributing to 100.00% of the total instances. Notably, the majority of instances fall within the categories of medium and high support, encompassing the entire dataset. The cumulative percentages provide valuable insights into the distribution of support levels; for example, the cumulative percentage at "Medium Support" signifies that 56.64% of the total instances have medium or lower support

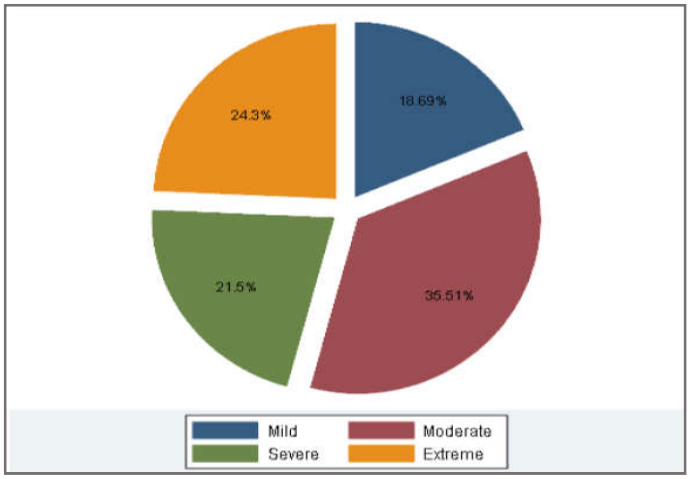


The Table 2 provides a detailed breakdown of support levels across different sectors, genders, and household sizes. In the sector analysis, Gashari exhibits the highest percentage of instances categorized as High Support (28.26%), while Rugabano and Rubengera show a relatively balanced distribution across Low, Medium, and High Support categories. Regarding gender, a slightly higher percentage of males fall under the High Support category (56.85%) compared to females (43.15%). In terms of household size, the smallest households (size 2) predominantly receive Low Support (8.7%), indicating potential variations in support needs based on household composition.

World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) for children and adolescents

The Figure 3 categorizes individuals based on the severity of their disabilities, revealing distinct levels: Mild disabilities account for 18.69% (40 individuals), Moderate disabilities constitute 35.51% (76 individuals), Severe disabilities make up 21.5% (46 individuals), and Extreme disabilities comprise 24.3% (52 individuals) of the total population under study. The Frequency column enumerates the number of individuals at each disability level, providing a clear breakdown: 40 with mild disabilities, 76 with moderate disabilities, 46 with severe disabilities, and 52 with extreme disabilities. The Percent column offers a proportional perspective, indicating that 18.69% of the population has mild disabilities, 35.51% has moderate disabilities, 21.5% has severe disabilities, and 24.3% has extreme disabilities.

Figure 3: Disability levels in children from Karongi district



Key findings highlighted poverty as a major impediment to providing medical care for disabled children and adolescents. Additionally, parents' attitudes, limited specialized centers, and communication barriers were identified as contributing factors to disparities in healthcare services. The lack of specific infrastructure, such as paths for those with joint disabilities or resources for the visual and hearing impairement, further aggravated the issue. Societal attitudes and beliefs about disability also played a significant role in perpetuating inequality. The stigma associated with having a disabled child led to social isolation and reluctance among parents to seek medical assistance. Misconceptions about the severity of disabilities hindered early interventions, delayed consultation and limited the ability of healthcare providers to address the real needs of disabled children effectively. A noteworthy factor contributing to inequality was the lack of specialized skills among healthcare providers to address the unique needs of children with joint disabilities. For instance, the absence of sign language proficiency hindered effective communication, making it very challenging for doctors and healthcare providers in general to communicate and address the medical needs of deaf-mute disabled children.

ETHICS APPROVAL

We sought ethical approval from Rwanda biomedical centre, ministry of health research division and Rwanda national ethics committee. Moreover, the study ensured anonymity and secrecy of the study participants. Before administering study tools, participants received a booklet outlining the goals of the study, the benefits of participating,

anonymity and confidentiality. They were also briefed that there would be no consequences if they choose to leave the initiative at any point and that their participation was entirely voluntary. we assured them that their data would be used only for research purposes and that their identities would not be disclosed to anyone apart from the authorized investigators. Both written and verbal informed consents were obtained from all participants, in addition to ethical approval and informed consent, all methods adhered to the Declaration of Helsinki's ethical principles for conducting human research.

DISCUSSION/CONCLUSIONS

There is a dearth of research on health needs of children and adolescent with disabilities in Rwanda.there is growing evidence that people with disabilities face enormous disparities in accessing healthcare and mostly preventive health and wellness program that may lead to chronic health conditions and reduced quality of life. Healthcare system need to create a conducive environment both for human resources and infrastructure to help children and adolescent with disability to access medical care [18]. Attending to their choices and preferences, treating them with respect, dignity and free of discriminationall are a sine qua non in responding to the health needs of children and adolescent with disabilities. Families and communities must also take part in advocacy campaigns to support children and adolescent with disabilities access to healthcare. Addressing the ppatients basic needs like access to food, transportation and housing are the stepping stones of reducing health disparities. To address inequality in healthcare services, we highly recommend awareness campaigns targeting parents and communities both public and private partnership, maintaining Adequate specialized centers, availability and affordability of prosthetic devices and providing regular and adequate training for healthcare professionals. Additionally, leveraging technology for efficient communication and service provision to children and adolescent living with disabilities.To adequately meet the needs of the children and adolescent living with disabilities, hard to reach and underserved communities, we must break the barriers and bring healthcare services close to them, health on wheels. the number of children and adolescents living with psychomotor impairment is highest in the Mutuntu sector where 65% are attributable to cerebral palsy based on the data collected by the Bienfait app, the Mutuntu sector in particular stands out with a very high proportion of children with cerebral palsy.highly proportion of congenital anomalies should raise high alert in screening for genetic conditions as well as nutritional intervention like micronutrients supplement to both pregnant women and under five children is paramount.

Acknowledgements:

The study was approved by Rwanda National Ethics Committee, the authors thank the study participants, friends and families and acknowledge the contribution of Bienfait project and Research for Development Rwanda for the successful implementation of the project.

LIST OF ABBREVIATIONS

CWD: Children living with Disabilities

WHODAS: World Health Organisation Disabilities Assessment Score

MSPSS: Multidimensional Scale of Perceived Social Support

RBC: Rwanda Biomedical Centre

MoH: Ministry of Health

RDHS: Rwanda Demographic and Health Survey

List of tables:

Table 1. General characteristics of study participants

Variable	Frequency	%
Residential sector		
Mutuntu	43	10.78
Murambi	46	11.53
Ruganda	60	15.04
Rugabano	56	14.04
Gashari	63	15.79
Rubengera	69	17.29
Bwishyura	62	15.54
Household size		
2	7	1.75
3	27	6.75
4	64	16
5	73	18.25
6	76	19
7	71	17.75
8	32	8
9	26	6.5
10	17	4.25
11	3	0.75
12	4	1
Household size for U18		
0	1	0.25
1	41	10.28
2	106	26.57
3	91	22.81
4	77	19.3
5	50	12.53
6	22	5.51
7	6	1.5
8	4	1
42	1	0.25
Sex of child with disability		
Male	230	57.64
Female	169	42.36
Age category of disabled children and adolescents		
0-6 years	119	29.82
7-12 years	198	49.62
13-18years	82	20.55

Table 2: Support level to disabled children across some demographic characteristics

Variable	Low support(%)	Medium support(%)	High support(%)
Sector			
Mutuntu	3(6.52)	18(12.41)	14(9.52)
Murambi	7(15.22)	15(10.34)	16(10.88)
Ruganda	8(17.39)	22(15.17)	21(14.29)
Rugabano	8(17.39)	21(14.48)	20(13.61)
Gashari	13(28.26)	18(12.41)	24(16.33)
Rubengera	4(8.7)	20(13.79)	32(21.77)
Bwishyura	3(6.52)	31(21.38)	20(13.61)
Sex			

Male	27(58.7)	86(58.9)	83(56.85)
Female	19(41.3)	60(41.1)	63(43.15)
HH size			
2	4(8.7)	2(1.37)	1(0.68)
3	7(15.22)	7(4.79)	9(6.12)
4	5(10.87)	30(20.55)	18(12.24)
5	10(21.74)	25(17.12)	27(18.37)
6	12(26.09)	20(13.7)	34(23.13)
7	4(8.7)	24(16.44)	27(18.37)
8	2(4.35)	12(8.22)	14(9.52)
9	0	14(9.59)	9(6.12)
10	1(2.17)	8(5.48)	7(4.76)
11	1(2.17)	2(1.37)	0
12	0	2(1.37)	1(0.68)

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