



SYSTEMATIC REVIEW

REVISED **Barriers to access and utilization of healthcare by children with neurological impairments and disability in low- and middle-income countries: a systematic review [version 2; peer review: 2 approved]**

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Abstract

Background: Neurological impairments (NI) and disability are common among older children in low-and middle-income countries (LMICs). We conducted a systematic review to examine the barriers limiting access and utilization of biomedical and rehabilitative care by children and adolescents with NI in LMICs.

Methods: We searched PubMed, Latin America and Caribbean Health Sciences Literature, Global Index Medicus, and Google Scholar for studies published between 01/01/1990 and 14/11/2019 to identify relevant studies. We included all studies reporting on barriers limiting access and utilization of preventive, curative, and rehabilitative care for children aged 0-19 years with NI in five domains: epilepsy, and cognitive, auditory, visual, and motor function impairment. Data from primary studies were synthesized using both qualitative and quantitative approaches.

Results: Our literature searches identified 3,258 reports of which 20 were included in the final analysis. Fifteen studies (75.0%) originated from diverse settings in sub-Saharan Africa (SSA). Factors limiting access and utilization of healthcare services in >50% of the studies were: financial constraints (N=17, 85.0%), geographical and physical inaccessibility (N=14, 70.0%), inadequate healthcare resources (N=14, 70.0%), prohibitive culture and beliefs (N=12, 60.0%), and inadequate

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education/awareness (N=11, 55.0%). Factors reported in <50% of the studies included competing domestic roles (N=4, 20%) and a lack of confidentiality for personal information (N=2, 10.0%). Very few reports were identified from outside Africa preventing a statistical analysis by continent and economic level.

Conclusions: Financial constraints, geographic and physical inaccessibility, and inadequate healthcare resources were the most common barriers limiting access and utilization of healthcare services by children with NI in LMICs.

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Keywords

healthcare, neurological impairments, disability, rehabilitation, resource-limited settings

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REVISED Amendments from Version 1

Introduction: We have broadened the introduction section to include the International Classification of Functioning, Disability and Health (ICF) framework to improve the justification of the need for this systematic review. **Methods:** Following the reviewers' recommendations, we have expanded the search terms to include the terms "OR cerebral palsy" to obtain studies on motor impairments that might have been missed out in the initial searches. We also have explained the checks that were conducted to ensure there was an agreement between the reviewers at the screening stage. In the analysis, more details are provided on the process of identification and classification of barriers limiting access to care by children with neurological impairments and disabilities using data obtained from the primary reports. **Results:** The total number of studies included in the Results section of the revised paper is 20 compared to 16 reports analysed in the previous version. We also have a higher number of titles/abstracts (N=3,258) compared to the number (N=3,074) reported in the former draft. We also present the quality of the studies report in this section. We have revised Figure 3 to reflect the effect of the expanded searches in the study selection process. We moved Table 1 from the Methods to Table 3 in the Results, and thereafter, renamed the other tables appropriately both in the text and the captions. We have revised Table 1, Table 2 and Table 4 to include information obtained from the additional reports identified by the expanded searches. As suggested by the reviewers, Figure 4 was removed from the paper in the revised manuscript because it was unnecessary. **Discussion:** We have revised the discussion section to incorporate interpretation of all studies identified and included in this systematic review. We have replaced the terms "anti-epileptic drugs" with "antiseizure medications" throughout the paper.

Any further responses from the reviewers can be found at the end of the article

Introduction

Globally, at least 300 million children live with some form of neurological impairment (NI) or disability, of which >90% originate from low- and middle-income countries (LMICs) (Olusanya *et al.*, 2020). The International Classification of Functioning, Disability and Health, ICF (WHO, 2001), and the International classification of functioning, disability and health: children and youth version: ICF-CY (WHO, 2007), provides a common language and framework to guide research and care of children and youth with NI and disabilities, globally. By integrating both the medical and social models of health and disease (biopsychosocial model (Engel, 1977)), the ICF conceptualizes child functioning as an interaction between the health conditions, environmental factors, and personal factors. Childhood NI and disability not only affects the health and education of the affected individual, but also, directly and indirectly, impacts the family, community, and the society (Patel *et al.*, 2013).

Considering the medical component of the ICF framework, known risk factors of NI and disability in children include adverse pregnancy and birth events such as prematurity and neonatal encephalopathy (Abuga *et al.*, 2021a), infections of the brain including malaria and meningitis, malnutrition, trauma,

and poverty (Banks *et al.*, 2017; Scherzer *et al.*, 2012). The affected children, especially those with moderate, severe or multiple disabilities, are vulnerable to infections and accidents which might necessitate hospitalization and subsequent rehabilitation (Moreau *et al.*, 2013). Unfortunately, there is a high treatment gap for NI and disability in LMICs ranging between 50–90% (Patel *et al.*, 2013). The most significant factors limiting the implementation of effective interventions in LMICs include (i) insufficient evidence on the delivery of interventions (ii) inadequate identification of the affected children, and (iii) a shortage of skilled professionals (Patel *et al.*, 2009). Besides, numerous factors limit access or utilization of available preventive, curative, and rehabilitative services by the affected children (WHO, 2011).

Primary preventive services such as nutritional supplementation and immunization have an established role in the prevention of NI (Groce *et al.*, 2014). Vitamin A supplementation and early childhood immunization against measles, rubella, and poliomyelitis substantially reduce the risk of developing NI (Maulik & Darmstadt, 2007), but also reduce morbidity in those that have NI. Secondary prevention involves early screening to identify those already with NI for treatment (or management) to alter the prognosis. Diagnostic tests such as the electroencephalogram (EEG) may help classify seizures and determine treatment (Bassili *et al.*, 2002). Tertiary and quaternary prevention includes treatment and rehabilitation, respectively, to prevent premature mortality, improve functioning, and quality of life. Corrective surgery for children with hearing impairments (Roland *et al.*, 2016) and antiseizure medications for children with epilepsy (Mbuba *et al.*, 2012) are widely documented curative/management options. Rehabilitative services to reduce activity limitation and to improve participation in respective communities include physiotherapy and occupational therapy. However, children from LMICs lack adequate access to the aforementioned continuum of healthcare due to multifarious barriers such as geographical inaccessibility, societal stigma, and financial constraints (WHO, 2011).

A range of barriers, both from the consumer's and provider's perspectives, may hinder uptake of biomedical services by affected children in LMICs (Figure 1). Poverty in families of children with NI and inadequate government funding limits the prioritization, availability, access, and quality of rehabilitative care (Bright *et al.*, 2018). Besides, prevailing cultural beliefs and societal perceptions shape caregivers' perceptions especially on the aetiology of NI, which affects decisions about the alternatives of care, and ultimately the prognosis of neurodisability (Zuurmond *et al.*, 2019). A 2015 report published by the World Health Organization (WHO) further highlights that people with NI usually experience discrimination at the point of care, which may discourage subsequent seeking of appropriate services (WHO, 2015). Measures such as decentralizing health systems have been proposed to bring services closer to the people and to reduce the geographical distance (distance decay) especially for rural-dwelling populations (Saltman *et al.*, 2007).

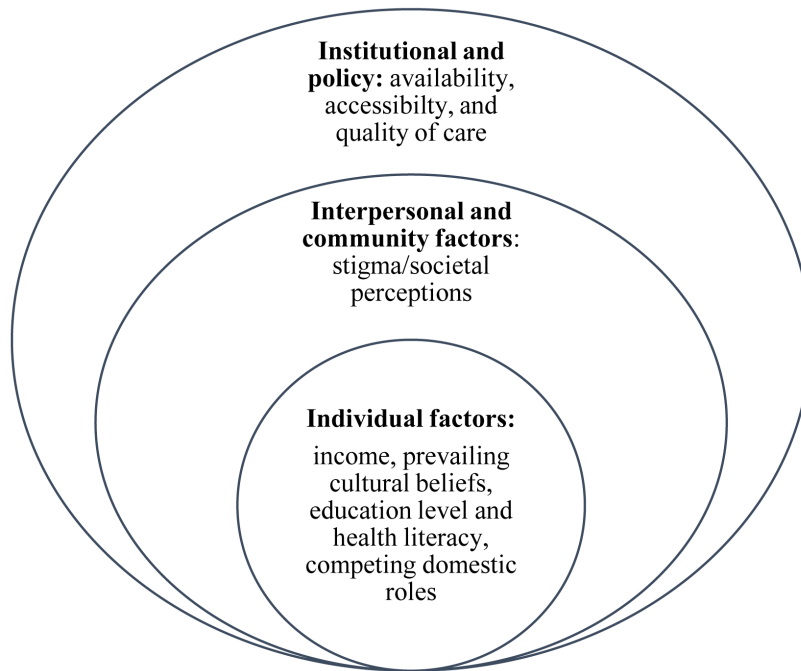


Figure 1. A modified socio-ecological model with layers of barriers limiting access/utilization of healthcare by children with neurodisability.

Some studies from LMICs have separately identified contextual factors that limit access and utilization of existing biomedical services by children with NI. The available evidence on barriers preventing the use of preventive, curative, and rehabilitative services by children with NI in LMICs remains fragmented. We, therefore, conducted a systematic review to collate and classify barriers limiting access and utilization of biomedical services by children and adolescents with NI in LMICs. Synthesized evidence from LMICs is required to inform policy and public health action to ensure equity in access and utilization of healthcare as enshrined in the agenda of the United Nation's sustainable development goals (Pettigrew *et al.*, 2015; Tangcharoensathien *et al.*, 2015).

Methods

Reporting guidelines

We used the National Health Service Centre for Review and Dissemination (CRD) recommendations (Booth *et al.*, 2010) and the preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines (Abuga *et al.*, 2021b; Moher *et al.*, 2009) to conduct this systematic review. We registered a protocol with the International Prospective Register for Systematic Reviews (PROSPERO), registration ID CRD42020165296 (28th April 2020).

Search strategy and inclusion criteria

We searched PubMed, Latin America and Caribbean Health Sciences Literature (LILACs), Global Index Medicus, and Google Scholar databases for reports published between

01/01/1990 and 14/11/2019 to identify relevant reports. These searches covered a period through which the burden of NI and disability has significantly increased, globally (Global Research on Developmental Disabilities Collaborators, 2018). The key search terms were 'neurological impairment' and 'access' or 'utilization' and 'healthcare services' as shown in Figure 2, with limits to human studies only.

Eligible studies included those of: (i) children and adolescents aged 0–19 years; (ii) children or adolescents with NI in five domains namely, epilepsy, and impairments in cognitive, hearing, visual, and motor functions; (iii) assessing access and utilization of healthcare services including preventive, curative, and rehabilitative care; and (iv) LMICs as defined by the World Bank (World-Bank, 2019). We excluded systematic reviews, reports, studies on adults, studies conducted in HICs, commentaries, and studies published in languages other than English.

Defining neurological impairment and disability

Neurological impairment was defined as a deficit of the central nervous system (CNS) resulting in functional limitation in five domains namely: epilepsy, and cognitive, hearing, visual, and motor impairments (Mung'ala-Odera *et al.*, 2006). Epilepsy was defined according to the International League Against Epilepsy's (ILAE) guidelines as the presence of two or more unprovoked seizures occurring more than 24 hours apart within the previous 12 months (Fisher *et al.*, 2014; Thurman *et al.*, 2011). A child with moderate or severe cognitive impairment refers to a child with a z-score below -2SD or -3SD, respectively

(access OR utilization OR use OR barriers OR limitation) AND
 (healthcare services OR medical services OR healthcare) AND
 (neurological impairment OR epilepsy OR cognitive impairment OR intellectual disability
 OR motor impairment OR cerebral palsy OR vision impairment) AND
 (low-income country OR middle-income country OR developing country OR developing
 nation OR Africa OR South America OR Asia OR third world)

Figure 2. Search terms used in the systematic review.

based on neuropsychological scores standardized to the normal population. Moderate motor impairment is defined as a difficulty in holding objects, dressing and sitting upright, or ambulant only with help, while severely impaired children include those unable to walk or have no functional use of the hands (WHO, 2011). Moderate hearing impairment refers to a 41–70dB loss in the best ear or difficulty in hearing with a hearing aid; severe impairment refers to greater than 70dB hearing loss or complete loss of hearing in the best ear (WHO, 2020). A child with moderate vision impairment has a visual acuity poorer than 6/18 while those with visual acuity poorer than 6/60 meters are classified as having severe vision impairment (WHO, 2019). However, there was a variation in the actual definitions used in the individual studies and most reports lacked information on NI severity. We, therefore, used these definitions as a formal guideline to verify the actual definitions used in the included reports.

Study selection, data extraction, and quality appraisal

Study selection was done in two phases. In the first phase, two reviewers (LM and JA) independently screened the reports identified by the searches by title and abstract for eligibility. The two reviewers compared the lists of the identified reports as to whether they met the predefined inclusion criteria and disagreements were resolved through consensus. In the second phase, both reviewers (LM and JA) examined the full-text of articles obtained from the first phase against the inclusion and exclusion criteria. Disagreements were resolved through consensus in discussions involving three reviewers (LM, JA and EC). We extracted data relevant for analysis using a pretested data extraction tool designed by the reviewers using guidelines from the PRISMA checklist. Extracted data included author details, study setting, study population, participant characteristics, the type of healthcare services sought, and barriers hindering access or utilization of the services by children with NI or disability. We assessed the quality of each study using the Joanna Briggs Institute (JBI) critical appraisal tools, which are distinct for cross-sectional, cohort, and qualitative studies (Munn *et al.*, 2014).

Synthesis of included reports

Eligible reports identified by the searches and the selection processes were both qualitative and quantitative in design. We,

therefore, used a mixed methods review process to synthesize evidence from the eligible studies. The qualitative component of the analytic phase involved the identification and classification of the barriers limiting access to healthcare as described in the primary studies. We grouped all eligible studies based on the domain of NI investigated, and then classified the barriers identified in the primary studies in a three-step process. In step I, three reviewers (LM, EC and JA) independently identified the emerging categories in all the data retrieved from the primary articles. Single or multiple quotes in the primary articles were sufficient because the articles themselves did not similarly present these barriers. In stage II, the three reviewers held a joint meeting to present and discuss all the identified categories, each at a time. Some categories were merged, and others were created to include reviewers' suggestions logically and comprehensively. In stage III, the reviewers held the final joint consensus meeting to review the previously created and discussed categories before writing the final report. This three-step process ensured that the classification process for the barriers identified in the primary articles was valid and reliable. We also identified verbatim excerpts from the eligible primary qualitative studies to represent the voices of the caregivers about their perceptions of the barriers to care for their disabled children. The quantitative component of the analytic phase primarily entailed determining the frequencies and proportions (percentages) of the identified barriers depending on the continent and economic level of the country of origin of the included primary studies. Services sought by children with NI were classified as preventive, curative, or rehabilitative.

Results

Search results

The database searches yielded 3,258 reports, of which 20 were eligible for the final analysis (Figure 3). Most (75.0%) studies were conducted in Africa while the rest originated from Asia. Over 60% of these studies originated from lower-middle-income countries (LMIs) while the remainder (<40%) came from low-income countries (LIs) and upper-middle-income countries (UMICs), respectively. There were more community-based studies (55.0%) compared with hospital-based reports (45.0%), and more qualitative studies (50.0%) than quantitative studies (45.0%) (Table 1). There were six (30.0%) studies on epilepsy, four (20.0%) studies on motor impairment/cerebral palsy, three

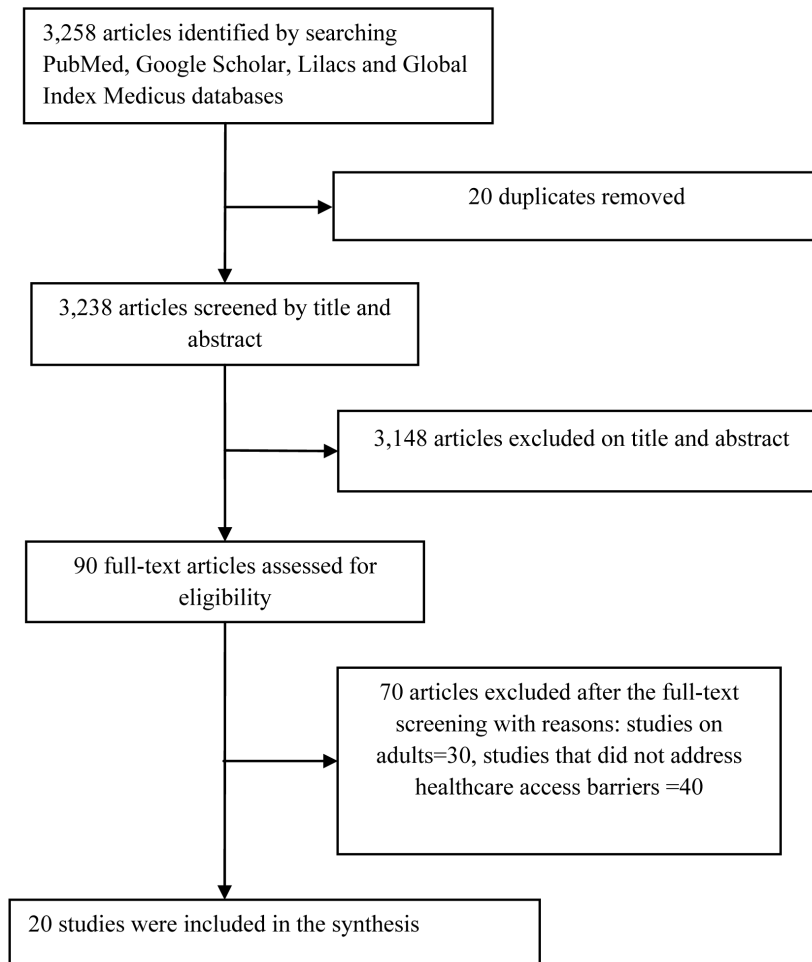


Figure 3. PRISMA flow diagram of the study selection process.

Table 1. Classification of the studies included by economy level and study setting.

Classification		Number of Studies (n=20)	The total sample size of participants in the study (n=7,607)
Continent	Asia	5 (25.0%)	5,095
	Africa	15 (75.0%)	2,512
World Bank country income classification	Low-income	3 (15.0%)	631
	Lower-middle-income	13 (65.0%)	1,561
	Upper-middle-income	4 (20.0%)	5,415
Study design	Cohort	2 (10.0%)	5,137
	Cross-sectional	7 (35.0%)	1,794
	Qualitative	10 (50.0%)	629
	Mixed methods	1 (5.0%)	47
Setting	Community	11 (55.0%)	6,085
	Hospital	9 (45.0%)	1,522

(15.0%) studies on hearing impairment, two (10.0%) studies on cognitive impairment/intellectual disability, one (5.0%) study on vision impairment, and four (20.0%) studies in more than one domain of NI (Table 2). The median quality score for quantitative studies (N=9) was 90% (range 37.5-90.0). Similarly, the median score for qualitative studies (N=10) was 90% (range 69.0-90.0).

Healthcare for children with neurological impairment

Rehabilitative services were sought in nine (45.0%) studies, treatment/management reported in seven (35.0%) studies, and preventive care reported in four (20.0%) studies (Table 2). Children with motor impairments/cerebral palsy or intellectual disabilities sought strength training, ambulation and speech therapy care from occupational therapy, physical therapy and mental health departments (Gobrial, 2012; He *et al.*, 2017) while rehabilitation for hearing impairment included the provision of assistive hearing devices (Merugumala *et al.*, 2017). Antiseizure

medication used in the management of seizures included phenobarbital (Bassili *et al.*, 2002; Mbuba *et al.*, 2012), phenytoin (Bassili *et al.*, 2002), sodium valproate (Bassili *et al.*, 2002), and carbamazepine (Bassili *et al.*, 2002; Mbuba *et al.*, 2012). Bassili and colleagues also identified the use of electroencephalogram (EEG) and computed tomography for the diagnosis or classification of epilepsy (Bassili *et al.*, 2002). None of the epilepsy reports identified the use of surgical services. Preventive services reported in three studies included the screening of HIV/AIDS (Yousafzai *et al.*, 2005), the provision of contraceptives for young adults with disabilities (Burke *et al.*, 2017), and screening services for children with hearing impairment (Bright *et al.*, 2017).

Barriers for healthcare (quantitative analysis)

The barriers identified from all eligible studies were classified, analysed, and reported based on seven all-inclusive themes namely: financial constraints, geographical inaccessibility

Table 2. General characteristics of studies eligible for inclusion in the systematic review.

First Author & year of Publication	Country	Study design	Domain studied	Type of services discussed
Alloh <i>et al.</i> , 2009	Cote d'Ivoire	Cross-sectional	Disabilities	Rehabilitative
Alrasheed <i>et al.</i> , 2018	Sudan	Qualitative	Vision	Preventive
Bassili <i>et al.</i> , 2002	Egypt	Cross-sectional	Epilepsy	Treatment/management
Burke <i>et al.</i> , 2017	Senegal	Qualitative	Disabilities	Preventive
Bright <i>et al.</i> , 2017	Malawi	Cohort	Hearing	Treatment/management
Carter <i>et al.</i> , 2012	Kenya	Qualitative	Epilepsy	Treatment/management
Gobrial, 2012	Egypt	Cross-sectional	Intellectual	Rehabilitative
He <i>et al.</i> , 2017	China	Retrospective cohort	Intellectual	Rehabilitative
(Jindal <i>et al.</i> , 2018)	India	Qualitative	Motor impairments/Cerebral palsy	Rehabilitative
Kirabira <i>et al.</i> , 2018	Uganda	Cross-sectional	Epilepsy	Treatment/management
Khoza-Shangase, 2019	South Africa	Qualitative	Hearing	Rehabilitative
Mbuba <i>et al.</i> , 2012	Kenya	Cross-sectional	Epilepsy	Treatment/management
(McConachie <i>et al.</i> , 2001)	Bangladesh	Mixed methods	Motor impairments/cerebral palsy	Rehabilitative
Merugumala <i>et al.</i> , 2017	India	Qualitative	Hearing	Rehabilitative
(Nuri <i>et al.</i> , 2019)	Bangladesh	Qualitative	Motor impairments/cerebral palsy	Rehabilitative
(Patel <i>et al.</i> , 2017)	Botswana	Qualitative	Motor impairments/cerebral palsy	Rehabilitative
El Sharkawy <i>et al.</i> , 2006	Kenya	Qualitative	Epilepsy	Treatment/management
Tataryn <i>et al.</i> , 2017	Malawi	Cross-sectional	Disabilities	Preventive
Wagner <i>et al.</i> , 2016	South Africa	Cross-sectional	Epilepsy	Treatment/management
Yousafzai <i>et al.</i> , 2005	Uganda, Rwanda	Qualitative	Disabilities	Preventive

and physical barriers, the inadequacy of healthcare resources, inadequate education/awareness, prohibitive culture/beliefs, competing domestic roles, and a lack of confidentiality/anonymity (Table 3).

The main factors limiting accessing/utilization of healthcare services in >50% of the studies were financial constraints (N=17, 85.0%), geographical inaccessibility (N=14, 70.0%), inadequacy of healthcare resources (N=14, 70.0%), prohibitive culture/beliefs (N=12, 60.0%), and inadequate education/awareness (N=11, 55.0%). Factors reported in less than half of the studies were competing domestic roles (N=4, 20.0%), and the lack of confidentiality/anonymity (N=2, 10.0%). We identified

very few reports originating from outside Africa which prevented statistical comparisons of individual reports by continents and economic level of the countries contributing primary studies in the analysis (Table 4).

Barriers for healthcare (qualitative analyses)

Financial constraints. Most caregivers could not afford the recurrent costs for the antiseizure medication (Carter *et al.*, 2012; El Sharkawy *et al.*, 2006; Kirabira *et al.*, 2018). “This hospital is good but sometimes you go there, get examined and prescribed for drugs and you need money for those drugs. So if you don’t have money, then you just remain with the illness”, reported a caregiver for a patient with epilepsy from

Table 3. Classification of barriers preventing access/utilization of healthcare by children with neurological impairments/disability.

Theme (category) of barrier	Criteria for inclusion
1. Financial constraints	Determined by whether the patient/caregiver was able to pay for biomedical services and all indirect costs incurred while seeking care.
2. Education/ awareness	Lack of/inadequate information or awareness from healthcare facilities about the availability of care services; or caregiver/patient unable to seek services due to limited education/information/health illiteracy.
3. Culture/beliefs	Caregivers or patients’ values and perceptions inhibiting seeking biomedical services or societal attitude influencing health-seeking behaviour
4. Geographical inaccessibility and physical barriers	Geographical inaccessibility described as the proximity of the healthcare facilities from the patient’s/caregiver residence. Inaccessibility also included the inability to access healthcare services due to physical disabilities and/or unfavourable infrastructural design of healthcare facilities or transport systems.
5. Inadequate healthcare resources and quality of care	The attitude of healthcare workers and availability of appropriate services/equipment such as expert consultation, clinical assessment, supply of critical drugs, laboratory equipment, and testing in the healthcare facilities.
6. Confidentiality/anonymity	Comprising privacy and protection of patient information of those seeking healthcare.
7. Childcare/competing domestic roles	Domestic roles such as childcare or taking care of the sick and elderly at home as competing roles for the caregivers.

Table 4. Barriers limiting healthcare access classified by continents and levels of income.

Barriers	Continent		Economic level		
	Africa	Asia	LMI	LI	UMIC
Financial constraints	13 (76.5%)	4 (23.5%)	10 (58.8%)	3 (17.6%)	4 (23.5%)
Geographical accessibility	12 (85.7%)	2 (14.3%)	9 (64.3%)	3 (21.4%)	2 (14.3%)
Inadequate healthcare resources	11 (78.6%)	3 (21.4%)	10 (71.4%)	1 (7.1%)	3 (21.4%)
Inadequate education/awareness	8 (72.7%)	3 (27.3%)	8 (72.7%)	2 (18.2%)	1 (9.1%)
Prohibitive culture/beliefs	9 (75.0%)	3 (25.0%)	7 (58.3%)	3 (25.0%)	2 (16.7%)
Competing domestic roles	2 (50.0%)	2 (50.0%)	4 (100%)	-	-
Confidentiality/anonymity	2 (100%)	-	2 (100%)	-	-

Abbreviations: LMI (low-middle-income), LI (low-income), UMIC (upper-middle-income).

a rural village in Kenya (Carter *et al.*, 2012). Secondly, transportation costs hindered poorer families from accessing healthcare (Carter *et al.*, 2012; Merugumala *et al.*, 2017; Tataryn *et al.*, 2017). A caregiver from India explained, “I know the center didn’t ask for money, but it is the effort to get here right? We have to pay for bus fare and that’s a lot for me. So, I left it even when they called us back” (Merugumala *et al.*, 2017). Indirect costs of healthcare included loss of work-time (Wagner *et al.*, 2016), loss of income (Bright *et al.*, 2017), and diversion of limited family resources for treatment (Carter *et al.*, 2012).

Geographical access. The main geographical factors limiting access were unfavourable terrain (Bright *et al.*, 2017), and distance decay (Burke *et al.*, 2017; Carter *et al.*, 2012; El Sharkawy *et al.*, 2006; Mbuba *et al.*, 2012; Tataryn *et al.*, 2017). Unsuitable infrastructural design such as the absence of ramps, unfavourable public transport systems, and a lack of wheelchairs was also identified (Merugumala *et al.*, 2017). “The journey itself is difficult because my son cannot walk yet, so if I don’t find an auto-rickshaw, I have to carry him all the way down the long road to the center. That is very tiring especially in the summer heat, but what else can I do?”, complained a caregiver from India (Merugumala *et al.*, 2017).

Availability of healthcare resources. Seventy percent of the reports cited either an inadequate number of healthcare facilities, understaffing, or a lack of equipment and medication. Patients had difficulties in getting an appointment in public hospitals as there were few trained experts in neurology (Alloh *et al.*, 2009; Alrasheed *et al.*, 2018) and rehabilitation. Poor diagnostic equipment and the unavailability of antiseizure medication in healthcare facilities were common for epilepsy patients (Carter *et al.*, 2012). Screening programs for children with hearing impairment were unavailable and rehabilitation facilities for motor impairment/cerebral palsy and intellectual disability were few and were located in urban centres (Gobrial, 2012; Khoza-Shangase, 2019; Merugumala *et al.*, 2017).

Education/awareness. Some caregivers lacked information on the causes and treatment of epilepsy (Carter *et al.*, 2012), and about the existence of healthcare services (Alrasheed *et al.*, 2018; Burke *et al.*, 2017; El Sharkawy *et al.*, 2006; Merugumala *et al.*, 2017; Tataryn *et al.*, 2017). Lack of health education programs was reported by caregivers for patients with epilepsy and visual impairments, respectively (Alrasheed *et al.*, 2018; Bassili *et al.*, 2002). Health illiteracy limited caregivers’ awareness about the availability of specialist services and delayed or hindered the diagnosis of hearing impairment and management of children with intellectual disability (He *et al.*, 2017; Merugumala *et al.*, 2017). Parents and health workers could not communicate with deaf adolescents using sign language and print material in health campaigns was not adapted for blind individuals (Yousafzai *et al.*, 2005).

Culture/beliefs. There were misconceptions about the cause of epilepsy where animistic beliefs were strongly held. “It is

said that it is witchcraft. She was bewitched, that is according to our customs. That is when you will go to a *mganga* [traditional health practitioner] because you want to untrap them”, explained a grandmother to a child with epilepsy in Kenya (Carter *et al.*, 2012). Alternative care including consultation of traditional health practitioners (THP) was preferred to biomedical care for childhood eye diseases (Alrasheed *et al.*, 2018). Societal stigma hindered access to (i) antiseizure medication by children with epilepsy (Kirabira *et al.*, 2018), rehabilitation for those with cerebral palsy (Jindal *et al.*, 2018; McConachie *et al.*, 2001; Patel *et al.*, 2017) (ii) access to contraception by adolescents with disabilities (Yousafzai *et al.*, 2005), and (iii) HIV/AIDS testing among young adults with physical impairments (Burke *et al.*, 2017). The dominant role of family elders in health-related decisions played a pivotal role where the grandmothers believed that deafness would resolve spontaneously (Merugumala *et al.*, 2017).

Competing domestic roles, and lack of confidentiality. Four papers reported that childcare and other competing roles such as home care for a sick relative were given a higher priority over the healthcare for a child with a disability (Bright *et al.*, 2017; McConachie *et al.*, 2001; Merugumala *et al.*, 2017; Tataryn *et al.*, 2017). Two studies (Burke *et al.*, 2017; Yousafzai *et al.*, 2005) identified the lack of confidentiality and privacy of personal information as patients with disabilities needed to be accompanied by caregivers during consultations.

Discussion

Overall, the main factors hindering access to healthcare by children with NI were financial constraints, geographical and physical inaccessibility, inadequate healthcare resources, prohibitive culture and beliefs, and lack of education or awareness, respectively. Other important but less frequently reported factors were competing for domestic roles for caregivers, and a lack of confidentiality for personal information. Our searches identified more studies in epilepsy, and we obtained fewer reports for the other domains of NI such as hearing impairments. The main form of care reported for epilepsy patients was provision of antiseizure medications; however, there was a lack of newer antiseizure medication and other treatment options such as epilepsy surgery. Rehabilitative services were the most common form of care for those with motor impairments/cerebral palsy and intellectual disability. Most studies originated from Africa and fewer studies were identified from other LMICs complicating valid comparison by continent and level of economic development.

Children with NI from impoverished families could not afford out-of-pocket payments for healthcare, a problem compounded by a lack of health insurance. Many families were forced to neglect healthcare to meet more pressing basic needs such as food and shelter. These can be addressed by expanding the scope of health insurance coverage to reduce out-of-pocket payments for healthcare in LMICs. Children with epilepsy could not regularly access antiseizure medication, a common challenge in developing countries that can be solved by establishing community-based services, outreach programs and reducing the prices of antiseizure medication in settings where they

are costly. Indirect costs such as loss of work time have a significant economic impact on these families as time intended to be spent earning an income is used to care for their children. A cycle of poverty and disability might explain the inability of most caregivers to afford expensive primary care for their children (Banks *et al.*, 2017). Wilmshurst and colleagues (Wilmshurst *et al.*, 2014), affirm the finding that management of children with NI is expensive, and the cost of healthcare is unaffordable for many impoverished families. Additional expenses such as public transport and indirect costs such as loss of income were observed in previous studies (Eide *et al.*, 2015).

Inadequate healthcare resources especially for rehabilitation were common in most African studies. Few rehabilitation experts were working in poorly resourced rehabilitation centres predominantly located in urban centres. The lack of specialist services for visually impaired children reflects a previously reported shortage of 3.7 ophthalmologists per one million people in LMICs, a figure which is substantially low compared to 76.2 per million people in high-income countries (Resnikoff *et al.*, 2020). These shortages can be resolved by investing in training and employing more rehabilitation experts. Lack of information and inadequate communication is a great challenge in LMICs. Ineffective communication between healthcare providers and patient/caregivers has previously been studied (Maloni *et al.*, 2010), and patients and caregivers with NI would benefit from effective and clear communication from service providers, including the use of sign language for the deaf. Proper information packaging, effective doctor-patient communication, and further investment in health promotion campaigns might create and sustain awareness about neurodisability and healthcare (WHO, 2018). It is also well-established that maternal education is strongly associated with the use of health services (Armar-Klemesu *et al.*, 2000), while illiteracy of caregivers presents difficulties in understanding instructions from care providers (Crabtree, 2007). Also, health education might play a critical role in supporting the previously suggested community-based outreach programs.

As seen in a previous study (Eide *et al.*, 2015) poor terrain and long geographical distance significantly reduced the likelihood that children with NI from remote areas were able to access healthcare. Also, a lack of environmental modification to cater to those with physical impairment limited access to healthcare in some studies. For instance, there was a shortage of wheelchairs, and public transport systems and hospital facilities lacked provisions for people with physical disabilities. Distance decay, a phenomenon where service utilization reduces with increasing geographical distances from the healthcare facilities can be addressed through decentralizing healthcare and equipping rural health facilities with appropriate healthcare and rehabilitation resources. Additionally, community-based rehabilitation has been recommended to complement the care provided by the existing healthcare systems (Iemmi *et al.*, 2015). While the convention for the rights of people with disabilities, based on the ICF framework, advocates for modification of the environment for the welfare of those with disabilities (WHO, 2001; WHO, 2011), these

recommendations have not been implemented in most LMICs. Governments must ensure disability mainstreaming in existing and future infrastructural development (such as the construction of ramps) and partnership with non-governmental/private entities in providing other forms of support (e.g. wheelchairs) for children with disabilities.

In terms of culture and beliefs, our results are similar to those from a Turkish study (Diken, 2006), where mothers who perceived child disability to be a result of curses were more likely to seek traditional interventions. Misconceptions and animistic beliefs on the cause of NI were strongly associated with visiting THP. There is a need to integrate THP into formal healthcare alongside strengthening community-based rehabilitation (Krah *et al.*, 2018). Attitudes from the patient/caregiver, healthcare provider, or societal perspectives were associated with decisions made by primary caregivers or children with NI regarding healthcare. For example, a lack of altruism and discrimination by healthcare providers, and a lack of privacy was observed in sexual and reproductive care for adolescents with disability (Banks *et al.*, 2017; Eide *et al.*, 2015). Education and training of healthcare providers on equality and diversity are imperative to address the discrimination in the context of physician-patient-caregiver relationships. There is also a need to train non-existent specialities (Bunning *et al.*, 2014) and capacity building of existing healthcare staff to be sustained (Maloni *et al.*, 2010).

Strengths and limitations

There were few studies identified by our searches, with most reports from Africa and none from South America. Logistical constraints e.g. subscription requirements limited the number of databases we could search as well as the translation of reports identified in other languages than English. Also, we acknowledge that our search strategy might have missed some studies because a range of commonly used etiological and disability terms may have changed over time in the existing literature. This will affect the generalizability of our findings, and specific studies are needed from unrepresented settings. Both quantitative and qualitative studies were eligible for analysis, but study design variability prevented the utility of purely qualitative or quantitative methods in this review. While children and adolescents represent a broad range of age groups possibly with different factors influencing the utility of healthcare, there was no standard reporting of barriers in the primary studies reviewed, which should be standardized in future working groups by expert panels or task forces. However, to the best of our knowledge, this is the first systematic review to synthesize evidence of barriers limiting access and utilization of preventive, curative, and rehabilitative care by children and adolescents with NI in multiple domains in LMICs.

Conclusion

Financial constraints, geographic inaccessibility, inadequate healthcare resources, poor communication/awareness, and cultural barriers were the most ubiquitous barriers limiting access and utilization of healthcare services by children with NI. There were more studies from sub-Saharan Africa where the use of rehabilitative care was more common. Expanding health

insurance coverage, improving infrastructure with the decentralization of healthcare, and adequate training and staffing of care facilities, combined with investment in structured health promotion are fundamental steps towards addressing these challenges.

Data availability

All data underlying the results are available as part of the article and no additional source data are required.

Reporting guidelines

Harvard Dataverse: PRISMA checklist for 'Barriers to access and utilization of healthcare by children with neurological impairments and disability in low-and middle-income countries: A systematic review'. <https://doi.org/10.7910/DVN/H2V167> (Abuga *et al.*, 2021b).

Data are available under the terms of the [Creative Commons Attribution 4.0 International license](https://creativecommons.org/licenses/by/4.0/) (CC-BY 4.0).

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Samson Gwer 

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This is a greatly improved draft.

The authors provide quality scores for the included studies. It would be great if they can complement this with a tabulation of the critical appraisal results, provided as supplementary material if there is a publication limit to the number of tables.

The authors should consider a statement on the role of the co-authors in undertaking the systematic review.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Child Neurology; Health Systems

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 02 February 2022

<https://doi.org/10.21956/wellcomeopenres.19467.r48192>

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Helen McConachie 

Population Health Sciences Institute, Newcastle University, Newcastle, UK

This important systematic review has been improved by the authors, and they have responded appropriately to the comments I made on the original version. I still would have liked to know what use was made of the quality rating (e.g. whether less weight was given to findings from papers judged to be of low quality). However, it is not necessary for this to be addressed in a further revision. This paper will, I hope, be helpful to service commissioners and providers in considering how to overcome barriers for families in accessing and utilising services for children with neurological impairments and disability.

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 05 July 2021

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Samson Gwer 

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In reviewing this paper, I take note of comments and suggestions by the first reviewer raising valid issues which I agree need to be addressed by the authors.

The systematic review analyzes and summarizes different types of studies with different levels of evidence. There needs to be a clearer articulation of the mixed methods review process that has likely been used in conducting the review. This should include an explicit description of the data extraction and data synthesis processes used for the qualitative and quantitative types of studies

The authors indicate that they assessed the quality of the included studies but they have not provided a summary of the assessment. There is scanty information about the included studies - this is important for transparency. The reader should be able to judge that the results presented are indeed the product of an unbiased analysis of considered and included studies.

I also take note of a minor item in the abstract for clarification: What do the authors mean by "Survivors of Childhood Mortality" in the first statement on the abstract?

Are the rationale for, and objectives of, the Systematic Review clearly stated?

Partly

Are sufficient details of the methods and analysis provided to allow replication by others?

Partly

Is the statistical analysis and its interpretation appropriate?

Partly

Are the conclusions drawn adequately supported by the results presented in the review?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Child Neurology; Health Systems

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 10 Jan 2022

Jonathan Abuga, Kemri-Wellcome Trust Research Programme, Kilifi, Kenya

Thank you very much for reviewing this paper and inviting us to address your comments and suggestions. We have addressed the comments and made a point-by-point response to each one of them as below.

Comment #1

In reviewing this paper, I take note of comments and suggestions by the first reviewer raising valid issues which I agree need to be addressed by the authors.

Reply: *Thank you for noting the valid comments and suggestions given by the first reviewer. We have addressed your comments and suggestions, including those given by the first reviewer, and revised the manuscript appropriately.*

Comment #2

The systematic review analyses and summarizes different types of studies with different levels of evidence. There needs to be a clearer articulation of the mixed methods review process that has likely been used in conducting the review. This should include an explicit description of the data extraction and data synthesis processes used for the qualitative and quantitative types of studies.

Reply: *We have provided additional information for quantitative and qualitative synthesis approaches on pages 7-8 of the revised paper. We've also described the list of variables that were extracted and the methods which were used in the data synthesis for qualitative and quantitative studies included in this review.*

Comment #3

The authors indicate that they assessed the quality of the included studies, but they have

not provided a summary of the assessment.

Reply: Thank you for this important observation, which was also noted by the first reviewer. We now provide a summary of the assessment of the quality of studies in the first paragraph of the Results section, on page 8.

Comment #4

There is scanty information about the included studies - this is important for transparency. The reader should be able to judge that the results presented are indeed the product of an unbiased analysis of considered and included studies.

Reply: We have now provided additional information about the included studies (Tables 1-4) to allow the readers to make an unbiased assessment of the results.

Comment #5

I also take note of a minor item in the abstract for clarification: What do the authors mean by "Survivors of Childhood Mortality" in the first statement on the abstract?

Reply: We intended to refer to children who survive the first five years of life in LMICs. For clarity, we have revised the sentence which now reads as follows. "Neurological impairments (NI) and disability are common among children residing in low-and middle-income countries (LMICs).

Competing Interests: No competing interests were disclosed.

Reviewer Report 06 April 2021

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Helen McConachie 

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This systematic review addresses an important topic, aiming to identify barriers which affect access to healthcare for children with neurodisability and their families. Identification of barriers allows the proposal and development of strategies to overcome such barriers, and the authors include this in the Discussion. The review identifies seven categories of barriers from the literature selected; it is likely to be the first systematic review of this topic. Thus the findings are useful for the field.

However, there are a number of limitations to the methods of the review which limit its comprehensiveness. This does not necessarily invalidate the findings concerning types of barriers, though others of relevance may have been missed. However, it does create bias in some of the

authors' statements concerning how frequently different types of conditions or disorders would be represented in the literature, and such references should be rewritten (e.g. the first sentence of the Discussion, and the second sentence of the Conclusion). Of limitations, first, the authors considered only papers published in English, in only four databases, and did not include grey literature or searches by key author surnames. Second, the search terms for neurodisability were limited mostly to 'impairment', i.e. apart from epilepsy. In the span of time searched (1990-2019), before the publication of the ICF in 2001, a range of etiological and disability terms would have been used. For example, a search on 'cerebral palsy' (not just 'motor impairment') would have yielded a number of additional papers examining barriers to service use in LMICs. It is not clear that the authors did a preliminary check that key expected papers were found by their search strategy, and the resulting focus on epilepsy studies in their results is not surprising. Third, two reviewers independently screened papers on title and abstract for eligibility, but there is no statement as to whether there was any check on agreement at this crucial stage. Fourth, the authors state they examined the quality of studies but how this information was used is not reported. Fifth, there is inadequate description of how the seven themes to classify barriers were derived. Was this drafted in advance, or from the data extracted? Was there any check on the validity/reliability of the classification? What type of evidence was used - were single quotes from a paper sufficient, or was the paper itself required to have presented categories? Thus not enough information is presented so that the systematic review could be repeated by others. Obviously, the authors cannot redo the review at this stage, but a fuller acknowledgement of limitations in the Discussion is necessary.

Overall, the review takes a rather narrow focus, and some of the writing seems to reflect a medical mind-set rather than considering the wider needs of the child in the family and community. For example, the first sentence of the Abstract describes a focus on "survivors of childhood mortality" rather than reflecting the multifactorial background of child neurodisability. Likewise, the first paragraph of the Introduction emphasises hospitalisation from accidents or infection and only moves to prevention and rehabilitation in the second paragraph. The Introduction does not present a very thorough justification of the need for the review, simply saying the evidence concerning barriers is fragmented. To my mind a broader introduction would have been beneficial - for example, I was surprised not to see any reference to the influential overview article by Patel *et al.* (2013 *Arch Dis Child*)¹ which also discussed barriers such as lack of evidence-based treatments and lack of identification of disorders.

Figure 4 is unnecessary.

References

1. Patel V, Kieling C, Maulik PK, Divan G: Improving access to care for children with mental disorders: a global perspective. *Arch Dis Child*. 2013; **98** (5): 323-7 [PubMed Abstract](#) | [Publisher Full Text](#)

Are the rationale for, and objectives of, the Systematic Review clearly stated?

Partly

Are sufficient details of the methods and analysis provided to allow replication by others?

Partly

Is the statistical analysis and its interpretation appropriate?

Not applicable

Are the conclusions drawn adequately supported by the results presented in the review?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Child disability; Systematic reviews

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 10 Jan 2022

Jonathan Abuga, Kemri-Wellcome Trust Research Programme, Kilifi, Kenya

Thank you very much for reviewing this paper and inviting us to address your comments and suggestions. We have addressed the comments and made a point-by-point response to each one of them as below.

Comment #1:

This systematic review addresses an important topic, aiming to identify barriers that affect access to healthcare for children with neurodisability and their families. Identification of barriers allows the proposal and development of strategies to overcome such barriers, and the authors include this in the Discussion. The review identifies seven categories of barriers from the literature selected; it is likely to be the first systematic review of this topic. Thus, the findings are useful for the field. However, there are a number of limitations to the methods of the review which limit its comprehensiveness. This does not necessarily invalidate the findings concerning types of barriers, though others of relevance may have been missed. However, it does create bias in some of the authors' statements concerning how frequently different types of conditions or disorders would be represented in the literature, and such references should be rewritten (e.g. the first sentence of the Discussion, and the second sentence of the Conclusion).

Reply: *Thank you very much for appraising our work and for identifying potential limitations in the methods section for our attention. In our reply to your comments numbered 6-8 below, we respond to each specific question about the identification and classification of barriers and the reasons why we focussed on the selected categories. We hope that these revisions have improved the paper.*

Comment #2:

The authors considered only papers published in English, in only four databases, and did not include grey literature or searches by key author surnames.

Reply: *Thank you for pointing out this limitation, which we now discuss in the discussion of the revised manuscript. This was a systematic review whose focus was mostly on peer-reviewed articles. This systematic review approach gives equal chances of article identification to both key*

and new authors. We had intended to include non-English articles but struggled to get translation assistance for various foreign languages, a consistent challenge in many of our previous reviews. Our searches, however, identified a critical number of reports published in sub-Saharan Africa (SSA), which we think might be representative of this region. We have acknowledged this limitation in the strengths and limitations section of the revised manuscript (page 17, lines 338-352).

Comment #3:

Second, the search terms for neurodisability were limited mostly to 'impairment, i.e. apart from epilepsy. In the span of time searched (1990-2019), before the publication of the ICF in 2001, a range of etiological and disability terms would have been used. For example, a search on 'cerebral palsy' (not just 'motor impairment') would have yielded a number of additional papers examining barriers to service use in LMICs. It is not clear that the authors did a preliminary check that key expected papers were found by their search strategy, and the resulting focus on epilepsy studies in their results is not surprising

Reply: We did a preliminary check of the expected studies and the search strategies and identified most of the key studies that we were aware of at the time of the initial search. While we acknowledge that our search strategy might have missed some studies given the limitations in the search terms and the changes in commonly used terminology over the review period, we believe that some studies of cerebral palsy would have described motor deficits/impairments in the text field of these reports, and would be identified since we did not restrict search terms by title, abstract or text. We, however, have conducted additional searches in the select databases using the additional search terms "OR cerebral palsy" for the same period and identified four additional papers that meet the inclusion criteria. Details of these four articles are now reflected in the methods, results, and discussion of the revised manuscript.

Comment #4:

The reviewers independently screened papers on title and abstract for eligibility, but there is no statement as to whether there was any check on the agreement at this crucial stage.

Reply: Thank you for this observation. At the screening stage, two authors (LM and JA) compared the list of reports identified by the searches as to whether they met the predefined inclusion criteria; all disagreements were resolved by consensus before proceeding to the next stage. This information is now provided on page 7, lines 113-114 of the revised manuscript.

Comment #5:

The author's state they examined the quality of studies but how this information was used is not reported.

Reply: We acknowledge this oversight in our report. We now report the median percentage scores, for instance, 90% (range 37.5-90.0) for quantitative studies, based on the Joanna Briggs Institute (JBI) critical appraisal tools in the results of the revised manuscript (see the first paragraph of the Results).

Comment #6:

There is an inadequate description of how the seven themes to classify barriers were

derived. Was this drafted in advance, or from the data extracted?

Reply: *Thank you for this important question. The seven themes into which we classified the barriers were based on data extracted from the first 10 articles meeting the inclusion criteria and were constantly updated with new emerging themes from the subsequent review of the remainder articles. For this reason, the categories (themes) we identified might only exclude other relevant categories not captured by our searches. We used a three-stage process to identify and classify barriers from the primary articles. In stage I, three reviewers (LM, EC, and JA) each independently identified the emerging categories in the data retrieved from the primary articles. In stage II, the three reviewers held a joint meeting to present and discuss the identified categories, each at a time. Some categories were merged, and others were created to include reviewers' suggestions logically and comprehensively. In stage III, the reviewers held the final joint consensus meeting on a separate date to review the created categories before writing the final report. We also identified verbatim excerpts from the eligible primary qualitative studies to represent the voices of the caregivers about their perceptions of the barriers to care for their disabled children. The three-stage process is now described on pages 7 and 8, in the Methods section, and pages 12-13 in the Results section of the revised manuscript.*

Comment #7:

Was there any check on the validity/reliability of the classification?

Reply: *As highlighted in our response to comment # 6 above, we addressed the inter-observer validity/reliability of our classification approach in a three-step process. We think that there is room for improving this thematic framework in future reviews.*

Comment #8:

What type of evidence was used - were single quotes from a paper sufficient, or was the paper itself required to have presented categories? Thus, not enough information is presented so that the systematic review could be repeated by other by others. Obviously, the authors cannot redo the review at this stage, but a fuller acknowledgement of limitations in the Discussion is necessary.

Reply: *As this was a systematic review to provide published data on the subject, single or multiple quotes identified in the primary article were sufficient; the report itself did not have to present the categories as defined by the reviewers as long as the barriers could be inferred from what was already provided. We provide this information in the Methods section (pages 7-8) of the revised manuscript. We also acknowledge the limitations of this approach in the Discussion.*

Comment #9:

Overall, the review takes a rather narrow focus, and some of the writing seems to reflect a medical mindset rather than considering the wider needs of the child in the family and community. For example, the first sentence of the Abstract describes a focus on "survivors of childhood mortality" rather than reflecting the multifactorial background of child neurodisability. Likewise, the first paragraph of the Introduction emphasises hospitalisation from accidents or infection and only moves to prevention and rehabilitation in the second paragraph.

Reply: Thank you for raising this important comment. We acknowledge the multidimensional perspectives of disability and how these have evolved. We have revised the abstract and the introduction sections, following your recommendations, to include the multifactorial background to child neurodisability based on the ICF framework, without deviating from the focus of our review, which was to identify barriers limiting access and utilization of biomedical services, including preventive, curative and rehabilitative care.

Comment #10:

The Introduction does not present a very thorough justification of the need for the review, simply saying the evidence concerning barriers is fragmented. To my mind a broader introduction would have been beneficial - for example, I was surprised not to see any reference to the influential overview article by Patel *et al.* (2013 Arch Dis Child)¹ which also discussed barriers such as lack of evidence-based treatments and lack of identification of disorders.

Reply: Thank you for this suggestion. We have broadened the introduction to justify the need for this systematic review. We have also included ideas from the landmark overview article by Patel *et al.* considering the context of this work. Please see the revisions on pages 4 and 5 of the revised manuscript.

Comment #11:

Figure 4 is unnecessary

Reply: Thank you for this observation. We have removed figure 4 and all references to it in the revised manuscript

Competing Interests: No competing interests to declare