SYSTEMATIC REVIEW

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: 1 approved, 1 approved with reservations]

Lucy W. Mwangi 1*, Jonathan A. Abuga 1,2*, Emma Cottrell 1, Symon M. Kariuki 1,3, Samson M. Kinyanjui 1,4, Charles RJC. Newton 1,3

1 Clinical Research (Neurosciences), Kemri-Wellcome Trust Research Programme, Kilifi, PO Box 230-80108, Kenya
2 Global Child Health Group, Emma Children’s Hospital, Academic Medical Center, University of Amsterdam, Amsterdam, AHTC, Tower C4, Paasheuvelweg 25 1105 BP Amsterdam, The Netherlands
3 Department of Psychiatry, University of Oxford, Oxford, Oxford OX3 7JX, UK
4 Nuffield Department of Medicine, University of Oxford, Oxford, Oxford OX3 7BN, UK

* Equal contributors

First published: 18 Mar 2021, 6:61
https://doi.org/10.12688/wellcomeopenres.16593.1
Latest published: 24 Jan 2022, 6:61
https://doi.org/10.12688/wellcomeopenres.16593.2

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
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.

**PROSPERO registration:** CRD42020165296 (28/04/2020)

**Keywords**
healthcare, neurological impairments, disability, rehabilitation, resource-limited settings
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).
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 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.

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 functions (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.

---

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

---
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.

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

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

References
Abuja JA, Kariuki SM, Abubakar A, et al.: Neurological impairment and

Carter JA, Molynieux CS, Mbuka CK, et al.: The reasons for the epilepsy
treatment gap in Kilifi, Kenya: using formative research to identify
interventions to improve adherence to antiepileptic drugs. Epilepsy Behav.

Crabtree SA: Family responses to the social inclusion of children with
developmental disabilities in the United Arab Emirates. Disabil Soc. 2007;

Diken IH: Turkish Mothers Interpretation of Child Disability of Their

Eide AM, Mandani H, Kaghol M, et al.: Perceived Barriers for Accessing Health
Services among Individuals with Disability in Four African Countries. PLoS
One. 2015; 10(5): e0125915.


Global Research on Developmental Disabilities Collaborators: Developmental
disabilities among children younger than 5 years in 195 countries and
territories, 1990–2016: a systematic analysis for the Global Burden of

Grobial E: Mind the gap: the human rights of children with intellectual


of children with cerebral palsy: exploring a cross-cultural view of
parents from India and Canada using the international classification of

Kotha-Shangase K: Early hearing detection and intervention in South
Africa: Exploring factors compromising service delivery as expressed by

Krah E, de Kruifj J, Ragno L: Integrating Traditional Healers into the Health
Care System: Challenges and Opportunities in Rural Northern Ghana.

Kotha-Shangase K: Early hearing detection and intervention in South
Africa: Exploring factors compromising service delivery as expressed by

mothers of children with disability in Bangladesh: implications for

interventions on health-seeking behaviors for children with epilepsy in

Stigler LL, Dietz M, Gulliford M, et al.: Limitations of using the Mental
Health Care Trak (MHC-Trak) to provide a common classification
system for mental health service systems in low- and middle-income

Wellcome Open Research 2022, 6:61 Last updated: 02 FEB 2022

Page 11 of 20
Open Peer Review

Current Peer Review Status: 

Version 2

Reviewer Report 02 February 2022

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

© 2022 McConachie H. This is an open access peer review report distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

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

https://doi.org/10.21956/wellcomeopenres.18287.r44564

© 2021 Gwer S. This is an open access peer review report distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Samson Gwer
1 School of Medicine, Kenyatta University, Nairobi, Kenya
2
Afya Research Africa, Nairobi, Kenya

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.
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

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