RESEARCH PAPER

Indignity, exclusion, pain and hunger: the impact of musculoskeletal impairments in the lives of children in Malawi

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Purpose: To develop a conceptual model representing the impact of musculoskeletal impairments (MSIs) in the lives of children in Malawi. Method: A total of 169 children with MSIs (CMSIs), family and other community members participated in 57 interviews, focus groups and observations. An inductive approach to data analysis was used to conceptualise the impact of MSIs in children's day-to-day lives. Results: The main themes that emerged were Indignity, Exclusion, Pain and Hunger. Indignity represents various affronts to children's sense of inherent equal worth as human beings, for example when bullied by peers. Exclusion refers to CMSIs being excluded from three core daily activities: school, play and household chores. Some CMSIs experienced Pain, for example as an outcome of striving to participate. Children with severe mobility impairments were at increased risk of Hunger, having less access to food outside the home and placing a burden of care on the family that could restrict household productivity. Household Poverty was therefore included in the model, as this household impact was inseparable from the impact on CMSIs. Conclusion: It is recommended that rehabilitation interventions are planned and evaluated with consideration to their impact on Exclusion, Indignity, Pain, Hunger and Household Poverty using multi-faceted partnerships.

Keywords: Africa, child disability, community-based rehabilitation (CBR), physical disability, qualitative, United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)

Introduction

The vast majority – 80% – of the estimated 200 million children with disabilities live in low and middle income countries (LMICS) [1,2]. Children with musculoskeletal impairments (CMSIs) from diverse conditions (e.g. clubfoot, cerebral palsy, burns, angular limb deformities) constitute a significant group among this population. In Malawi, almost half of people with disabilities have a physical disability (43.1%), over a third (38.6%) are aged 0-20 yrs, and onset of disability was reported to be at birth or before 10 years old in the majority of people (59%) [3]. While there is no specific data for the prevalence of CMSIs in Malawi, a recent survey demonstrated that more than 1 in 50 (2.58%) children in Rwanda have a MSI, over 40% being moderate to severe [4]. Yet despite the great need, CMSIs have little or no access to even basic rehabilitation services [5].

Since the adoption of the UN Convention on the Rights of Persons with Disabilities (UN CRPD, 2006), there is now increasing international commitment to deliver comprehensive rehabilitation to adults and children with disabilities - ‘particularly in the areas of health, employment, education and social services’ (Article 26) [6]. Over ninety countries including low-income countries such as Malawi have legally committed themselves to delivering comprehensive

Implications for Rehabilitation

- Rehabilitation interventions in Malawi and similar developing nations would benefit from being planned and evaluated with attention to their impact on Exclusion, Indignity, Pain, Hunger, and Household Poverty.
- To this end the development of new evaluative instruments for children with disabilities in these settings is needed and should be based on empirical evidence including the concepts presented in this paper.
rehabilitation. More recently, the World Health Organisation (WHO), International Labour Organisation, United Nations Educational, Scientific and Cultural Organization, and the International Disability Development Consortium (IDDC) jointly published the CBR Guidelines which also emphasize the need for a comprehensive approach to rehabilitation to ensure that people with disability can access and benefit from health, education, livelihood and social sectors with particular focus on empowerment [7].

However, a major limitation in implementing comprehensive and effective rehabilitation for CMSIs in LMICs is that there is very little evidence about:

1. How their lives are affected and what matters to them
2. What services or interventions actually work in terms of making a real difference in their lives

Evidence on the first question is needed before one can address the second question in a meaningful and robust way, using valid and reliable outcomes measures. Several outcomes measures have been developed to evaluate quality of life (e.g. WHOQOL [8]) and disability (e.g. WHODAS [9]) among adults in low-income countries, and there are many instruments targeting children with disabilities and MSIs originating in high-income countries [10–18]. Yet equivalent instruments have not been developed and/or validated for CMSIs and other disabilities in low-income countries. When such client-centred tools are developed or cross-culturally adapted, it is essential that they are based on conceptual frameworks that are valid to the target populations in low-income settings. The conceptual framework must represent what is important to CMSIs in their day to day lives.

In other words, the starting point for planning and evaluating comprehensive rehabilitation in LMICs is to have a comprehensive understanding of how CMSIs’ lives are affected in the first place. The aim of this study was to develop a conceptual model representing the impact of MSIs in the lives of young children in Malawi that can be used to plan effective rehabilitation interventions and develop valid and reliable outcomes measures to evaluate them.

**Methods**

The study was implemented by a research team based at neighbouring institutions of the Beit Cure International Hospital (BCIH, an orthopaedic hospital) and the University of Malawi’s College of Medicine (COM) in Blantyre. Local stakeholders including disabled people organisations (DPOs, e.g. Federation of Disability Organisations in Malawi (FEDOMA), Parents of Disabled Children Association in Malawi (PODCAM)), service providers (e.g. Malawi Council For The Handicapped (MACOHA), Malawi Against Physical Disability (MAP), Feed the Children (FTC), Save our Souls (SOS)) and other community-based organisations (CBOs) participated during various stages of the study: at the beginning at a launch meeting; during implementation as participants and in recruiting other participants; at the end during dissemination workshops.

This study was approved by the ethics committees of COM and the London School of Hygiene and Tropical Medicine.

**Sample**

Qualitative data was collected from a purposive sample (n = 169) of CMSIs (2–10 yrs, n = 34), their older siblings (age 8–16 yrs, n = 23) and parents/guardians (>18yrs, n = 56); adults who experienced childhood MSIs (n = 10); teachers (n = 12); health workers (n = 19); and community leaders (of both general and disabled communities, n = 15). CMSIs, siblings and/or guardians from the same families were included for triangulation of data. Between 1 and 3 members (n = 113) of 75 families with a child with MSI participated.

Participants were recruited in 4 districts of Malawi representing both farming (Blantyre, Lilongwe) and fishing (Zomba, Salima) livelihoods and both rural and urban settings. Permissions from local authorities (e.g. chiefs, department of health) were obtained, following which meetings with service providers (including community-based rehabilitation, CBR), health surveillance assistants, members of DPOs, and CBOs were held. During these meetings, volunteers were asked to identify CMSIs in their communities and collect relevant information about them (age, gender, anatomical site of MSIs, other impairments, language spoken, contact/ location of residence) using a standardised screening tool. The research team used the same tool to collect information about BCiH inpatients and outpatients at outreach clinics.

The information from this screening tool was compiled into lists and used to systematically select participants using predefined criteria. Among all participants (n = 169) we aimed for (and achieved) a roughly equal representation of gender (43% male) and a majority representation of rural residents (67% living outside a city/town/Boma). Twenty-eight percent lived in Blantyre, 30% in Lilongwe, 12% in Salima, 22% in Zomba, and 8% in other districts.

Among the 75 CMSIs represented by themselves and their families (guardians/siblings), we aimed for (and achieved, see Table I) a roughly equal representation of gender and age, and representation of children with MSIs affecting different

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sub-groups</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>2–5 yrs</td>
<td>35</td>
<td>46.7</td>
</tr>
<tr>
<td></td>
<td>6–10yrs</td>
<td>40</td>
<td>53.3</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>32</td>
<td>42.7</td>
</tr>
<tr>
<td>Impairments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lower limb(s) only (LL)</td>
<td>26</td>
<td>34.7</td>
<td></td>
</tr>
<tr>
<td>Upper limb(s) only (UL)</td>
<td>11</td>
<td>14.7</td>
<td></td>
</tr>
<tr>
<td>Spine/trunk only (SP)</td>
<td>5</td>
<td>6.7</td>
<td></td>
</tr>
<tr>
<td>Combination of UL/LL/SP</td>
<td>20</td>
<td>26.7</td>
<td></td>
</tr>
<tr>
<td>Multiple impairments (MULTI)§</td>
<td>13</td>
<td>17.3</td>
<td></td>
</tr>
<tr>
<td>School attendance</td>
<td>Going to school</td>
<td>43</td>
<td>57.3</td>
</tr>
<tr>
<td>Access to services</td>
<td>Not accessed specialist services</td>
<td>19</td>
<td>25.3</td>
</tr>
<tr>
<td>Intervention Status</td>
<td>Post-intervention</td>
<td>51</td>
<td>68</td>
</tr>
</tbody>
</table>

§MULTI = COMB + other impairment(s) (e.g. cognitive/visual/hearing); 4 children were reported to have cognitive impairments, 2 children were reported to have hearing impairments (affecting speech), and 7 children were reported to have cognitive impairments with visual and/or hearing impairments as well.
The average number of participants per FGD was 6 (range 3-10).

IDI = in-depth interview; FGD = focus group discussion, OBS= observation.

Table II. Data collection methods.

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>IDI</th>
<th>FGD</th>
<th>OBS</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children with MSIs (2-5 yrs, CMSI)</td>
<td>8</td>
<td>8</td>
<td></td>
<td>16</td>
</tr>
<tr>
<td>Children with MSIs (6-10 yrs, CMSI)</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Siblings (S)</td>
<td>9</td>
<td>3</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>Parents/guardians (P)</td>
<td>10</td>
<td>8</td>
<td></td>
<td>18</td>
</tr>
<tr>
<td>Adults with MSIs (A)</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Teachers (T)</td>
<td>2</td>
<td>1</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Health Workers (HW)</td>
<td>2</td>
<td>2</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Community Leaders (CL)</td>
<td>2</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>26</td>
<td>21</td>
<td>10</td>
<td>57</td>
</tr>
</tbody>
</table>

IDI = in-depth interview; FGD = focus group discussion, OBS= observation.

The broad assumption was that multiple anatomical sites and additional impairments constituted more severe disability than single-site MSIs only. The underlying conditions were diverse and included (amongst others): polydactyly (extra digits), burn contractures, bow legs, and cerebral palsy. To gain the experiences of children in a range of likely situations, children that had not accessed mainstream specialist services (i.e. referred past their local health centre), children who were pre-intervention, and children who were not schooling were actively selected as well as those who had accessed all these services.

Data collection

Three methods of data collection were used in 57 data collection events (Table II): in-depth interviews (IDI), focus group discussions (FGD) and observations (OBS).

The 57 events took place in the homes of participants (n = 24), rehabilitation institutions (n = 20), CBO/CBR premises (n = 10), and other public places (n = 3). Informed consent (participants >18 yrs) and assent (participants 6–17 yrs) took place at the beginning of each event using signatures or thumbprints. Refreshments and reimbursements for travel/time were provided. Participants were interviewed and observed mainly by one Malawian lecturer at COM (VJ) with experience of qualitative data collection. IDIs and FGDs were audio-recorded.

Topic guides for IDIs/FGDs started with ice-breaker questions which for children was ‘Tell me about your best friend?’ Subsequent questions included: ‘What makes you happy/sad?’ ‘What’s a good/bad day for you?’ ‘Tell me everything you do in the morning/afternoon, step-by-step,’ ‘Tell me about the treatment you have received?’, ‘How have things changed?’ ‘If you were given the power to change three things in your life, what would you change?’ Discussions ended with ‘What do you think that people right here in your community could do to help children with disabilities?’ Topic guides for other stakeholders were based on similar questions but tailored to their positions [19].

CMSIs were observed at home for 2–4 hours. The researcher took on an onlooker role with as little interaction with the child as possible [20]. Notes were recorded in English afterwards using a standard record form with 4 sections (background; summary of events; findings; reflections).

A photo-interview technique [21] where families were given disposable cameras to take photos before being interviewed was explored in 3 families, but found to be unfeasible because of the extra time required to use this technique.

Data analysis and development of model

Audio-recordings of all IDIs and FGDs were transcribed verbatim in Chichewa and translated into English by a team who were specifically trained for this task. The quality of the transcriptions and translations were systematically checked by the research team, and all the transcripts (showing both the Chichewa/English) were further reviewed and annotated together by both Malawian and English researchers responsible for the analysis (YA, VJ) to ensure that an accurate interpretation could be made from the English. All transcripts were then imported into NVIVO 8.

A thematic analysis was undertaken using an inductive approach, whereby the conceptualisation of themes was grounded in the data itself [22]. Following initial coding of a subset of transcripts (n = 8) to free nodes by two researchers (YA, SS), the nodes were re-conceptualised and structured into hierarchical (tree) nodes. The remaining transcripts were then systematically coded to this structure by two researchers (YA, SS). Reports of the empirical data under each code were then re-read and analysed with a view to identifying the important ways in which children’s lives are affected by having an MSI. Themes and sub-themes were developed to represent the main concepts of impact and the different ways that these arose, respectively. Themes were more abstract (e.g. Exclusion), sub-themes more descriptive (e.g. Left Behind).

Figure 1. Model of the impact of MSIs in the lives of children in Malawi (and their families).
Results

The final conceptual model (Figure 1) shows the major themes of impact (in upper case) and sub-themes (lower case) characterising the various ways in which the major concepts arose. It includes the impact of MSIs on the household as well as children, as it emerged that the two were intertwined. The model is explained below in sequence with the numbers in Figure 1.

Indignity

All stakeholders identified that an important issue affecting CMSIs was various affronts to their sense of inherent and equal worth as human beings. For example in relation to verbal abuse from family members a mother wished for people ‘showing her love and care so that she feels she is a human being like everybody is’ (Parent/118/IDI/70). These affronts are described by the 4 sub-themes below; see also Table III.

Mocked and bullied (1)

One of the main sources of indignity for all CMSIs - regardless of the site and severity of impairment - was being mocked and bullied by peers. This included verbal assaults, staring, mimicking, laughing and singing about body parts/disability/movement, using derogatory terms such as ‘cripple’ and accusing the child/family of sorcerous endeavours. Mockery occurred during fights with friends and unprovoked and deliberate bullying of CMSIs. Starting a new school away from the home community was a particularly vulnerable time for mocking/bullying:

‘at school [F. OK], the child reported that…[name] they are telling her that her she should scratch her own face but see the way she is, so she felt mocked, but here at home, her friends are very familiar with her’ (Parent/136/FGD/S3. UL, 2-5)

Abused (2)

Evidence indicated that most indignity arose between child-child rather than adult-child interactions. However, parents in the community were blamed for being complicit when CMSIs were mocked and some adults including family members were directly responsible for verbal and physical abuse of CMSIs. This included being beaten because they could not do things ‘properly’ (Table III) and being told that they were worthless:

The child's father [F. yes] his sisters on that day, they really ill treated her, they said ah, there is nothing good here, they should have thrown you away that time, you should have been a stillborn. (Parent/??/FGD/11).

In addition, a health worker reported that girls with MSIs were at risk of sexual abuse (Table III); this was not mentioned in discussions with families.

Humiliated and degraded (3)

Several parents, teachers and health workers identified the dependency of some CMSIs for self-care, particularly toiletting, as being humiliating for their children (Table III). These tended to be children with severe mobility impairments. Humiliation was described as shyness or self-consciousness on the part of the children, or a breach of privacy, particularly as they grew older.

In reaction to these offenses, CMSIs complained to teachers/parents, cried, asked for the impaired body part to be chopped off (in one instance), and many also fought back physically. Several participants including CMSIs identified being mocked, beaten and insulted as the things that made them sad or disappointed. Given the hypothetical power to change 3 things, this behaviour of others towards them was one of the things that some CMSIs wished to change.

Table III. Indignity - Data demonstrating the four subthemes underlying Indignity.

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mocked &amp; Bullied</td>
<td>F. I would like that you should explain to me those times when you are disappointed… (…)… C/139/FGD/62. 'People say you the disabled you don't talk [F. hm] they took you to practice witchcraft?… (…)… They say I fell as I was practicing witchcraft'</td>
</tr>
<tr>
<td></td>
<td>F. Tell me what makes you disappointed when you are disappointed? C/004/FGD/2. When somebody beats me up… (…)… When a friend starts using foul language at me 'The friends provoke him by making fun of him when he falls down because of his arm. So when they mock him, it pains him very much [F. Ok] So when it pains him he starts shooting stones at them or beating them up or crying because he has a lot of strength' (P/135/FGD/53)</td>
</tr>
<tr>
<td></td>
<td>'I like me to my part I was just insulted, when the physically able, they see you passing by and they would compete, those little physically able children, in staring at you as if they were watching TV and have never seen you before so that was hurting' (A/015/FGD/09)</td>
</tr>
<tr>
<td>Abused</td>
<td>'even adults do mock the child when playing especially when they see the child has no balance' (P/114/FGD/60)</td>
</tr>
<tr>
<td></td>
<td>The child's father [F. yes] his sisters on that day, they really ill treated her, they said ah, there is nothing good here, they should have thrown you away that time, you should have been a stillborn. (P/114/FGD/11)</td>
</tr>
<tr>
<td></td>
<td>Maybe so much to a female child, she can face a more problems than a boy child. I am talking in terms of like sexual abuse sometimes… (…)… If she is staying with some other people at home, you find that they are sexually abusing her. (HW/044/FGD/16)</td>
</tr>
<tr>
<td>Humiliated &amp; Degraded</td>
<td>She feels sorry for herself and she is full of shyness because sometimes she does not want to be taken out of the house whilst naked… (…)… She refuses to go out into the open (Emmm) when you put her down she points with her hands that she wants to put on clothes (P/072/ID/34)</td>
</tr>
<tr>
<td></td>
<td>Toileting, she has many problems. (…)… If I have gone away, (…)… she remains behind with her fellow sibling, she just soils herself. What else can she do? Her friends cannot manage to lift her. (P/118/IDI/70)</td>
</tr>
<tr>
<td></td>
<td>For that child to use pit latrine it is really a challenge because you can imagine, in a pit latrine toilet, the child lying straight on the ground (HW/040/FGD/16)</td>
</tr>
<tr>
<td>Left Out</td>
<td>See Table IV</td>
</tr>
</tbody>
</table>
Toiletng at school was mentioned as a particularly degrading experience for children with mobility impairments, including those in wheelchairs. Pit latrines at school were highlighted as very dirty and unhygienic places, posing a significant barrier to children who had to crawl or lie on the floor to reach them. Teachers and peers carrying/holding children over the pit latrines was also humiliating.

‘He was saying he wants porridge but fears where to relieve himself when need arise. This is so because it is found that the toilets are dirty, the children do not use the hole when urinating but just use every place in the toilet…. (…)… how will someone get off a wheelchair when the urine is just dripping all over the place’ (Teacher/001/IDI/1)

Left out (4)

Being left out of activities by peers, parents and teachers was a major cause of Exclusion and is described in further detail below. However, being left out was also a key source of Indignity:

‘The teacher had pity on the child just leaving her out without asking her questions. Even if she raised a hand, she was not given a chance to answer but the teacher pretended not to see her…. (…)…The child complained that the teacher did not see her as a human being in the classroom.’ (Health Worker/044/FGD/16)

Exclusion

Three participatory activities clearly emerged as being central to the daily lives of all children in Malawi whether able-bodied or disabled: playing with friends, going to school, and doing household chores. These 3 activities were perceived to be important because they brought children daily happiness and were valued as opportunities for socialising among peers, sharing responsibilities within the family, learning life skills and gaining qualifications required for future self-reliance, and developing physical strength, flexibility and health. It also emerged that they were important opportunities for accessing food outside the home.

Despite their impairments, children even with multiple and severe impairments had friends and were generally included in play (at least at home), were perceived to participate well in playing, and strove to participate to their fullest potential. Observations of CMSIs in their homes indicated this to be generally true when other children were around. (CMSIs were also observed to spend time playing alone, sometimes when peers were not around, other times because they were absorbed in their own activity.) However, CMSIs could experience many challenges when trying to participate in these activities as evidenced by the sub-themes below and in Table IV.

Withdrawal and abstaining (5)

Indignity was a major cause of Exclusion for children with all types of MSIs. The indignity felt by some CMSIs was evidently so strong, that many were compelled to withdraw temporarily or permanently from participation. Sometimes this was enforced as protective measures by parents. Many CMSIs withdrew or abstained from playing with friends and/
or dropped out of school because of mocking, bullying and/or having to use the pit latrines.

‘Likewise at school a while ago her friends were speaking bad things to her and she stayed one week at home refusing to go to school (F. oo!) she said she will not go again to school’ (Parent/118/IDI/70)

One parent complained that the teacher kept bringing her child home early because of mocking, others complained that their children didn’t learn anything on days they were mocked, and a teacher spoke of how CMSIs would not actively participate in class for fear of being laughed at. Thus, for CMSIs maintaining active participation at school was a challenge.

Let down (6)
Some CMSIs were let down by their bodies while striving to participate with others in all activities, and this was perceived to restrict their full participation. Some CMSIs affecting their lower limbs were not able to run, jump and climb as effectively as their friends:

‘When we are chasing each other and I fall down and break my leg’ (CMSI/004/FGD/2)

Children with impairments affecting the upper limbs were reported to have restrictions in climbing trees, playing handball, clapping, and one guardian also explained how her 4 year old child, who did not have any bones in his right arm, also complained of falling over:

‘what disappoints this one is falling down when he is running with his friends [cough] since the other side is not strong, so he really falls down’ (Parent/137/FGD/53)

Left behind (7)
School, play and household chores all involved venturing away from home and this was a major challenge for children with mobility impairments. During play children would not stay in one place but move between geographical locations (e.g. to each other’s homes/other places in the community), and the distances and terrains to schools, bore holes, maize mills, and farms were often incompatible for children with mobility impairments. Being physically left behind was a problem mainly for children with lower limb impairments but also a child with a spinal impairment:

‘what troubles her is mainly on the side of school, she does not go to school because she walks with difficulty’ (Parent/106/FGD/50)

Similar problems were faced within school grounds. Some children with mobility impairments were left behind in the classroom while others went out for recess and assembly. A child with cerebral palsy and her mother confirmed this:

‘…no they just leave me in class …(…)…all my friends get out’ (C/118/IDI/70)

‘All the classmates go outside the class except for her…(…)… she stays the whole day up to the time they knock off’ (P/118/IDI/70)

Left alone (8)
Some children with severe mobility impairments were left (or locked) alone at home while their families went out to work or school (Table IV).

You have the desire to stay at home and take care of the child but you think about what will happen to the work at the garden. So sometimes we lock the child in the house… (Parent/029/FGD/11)

Leaving CMSIs at home alone emerged mostly as a forced and difficult decision in families trying to make ends meet, rather than an issue of deliberate neglect or abuse. However, a health worker did describe the case of a CMSI who had been locked in a room to die by her mother because her husband first divorced her and then her new partner did not like the disabled child.

Being left alone while parents went out to work was suggested to be a widespread problem. Families in both rural and urban areas spoke of doing this, and the fact that a child with burns had acquired her MSIs while left alone suggested it could be a problem in families of able-bodied children as well.

Left out (9)
Many CMSIs were left out of activities by others. Some parents left CMSIs out of household chores, some untrained teachers left CMSIs out of learning activities and physical education, and peers sometimes left them out of games if they couldn’t play properly. These discriminatory behaviours, especially by parents, were sometimes described as ‘overprotection’ and seemed to result from a combination of feelings of pity for CMSIs and assumptions that they were unable to do things. Regardless of the motives, these behaviours were perceived by children as discrimination and caused both Exclusion and Indignity (see above).

‘my child in the end said why do you discriminate me? …(…)… Discriminating that the child should not do any work because of having an impairment. (F. Like doing what?) like sweeping like he was saying, cooking because we would say the food would not be well prepared’ (Community Leader/026/FGD/10)

Pain (10)
Several CMSIs said that they did not feel any pain and several family members said their children did not complain or show any signs of pain. However pain was an important outcome for other CMSIs, including CMSIs affecting the lower limbs, upper limbs, and spine. Pain was sometimes a side-effect of the condition, an intervention or being carried (Table V), but often arose as children strove to participate to their full potential:

‘I am having problems…(…)… When I try to walk, I feel pain and when this thing starts paining my legs seize up …(…)… And if I try to carry a baby on my back, I feel pain’ (CMSI/119/IDI/51)

The pain arising through participation in turn was a cause of Exclusion, limiting children’s participation (see Table IV ‘Let down’).
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Table V. Pain.

| Impact of childhood physical impairments in Malawi |

In the past I used to feel pain when walking but now when I walk with the clutch, I never feel more pain (C/111/FGD/60)

When he runs too much he cries…(…)… he feels pain in the legs (S/061/FGD/29).

‘when you wake up in the morning and you stretch him he says it's painful. Painful mmm it hurts [F. umm] he talks about the knee'. (P/076/FGD/37)

‘…the space in between the legs…(…)… is just too small [F. it is too small] when I'm trying to put her on my back she feels pain, I need to pin her legs like this’ (P/118/IDI/71)

During the first days of putting on calipers I could feel so much more pain than ever before’ (CL/023/FGD/10)

Table V. Household poverty.

| Impact of childhood physical impairments in Malawi |

It's is true this affects us unlike other families that don't have disabled children, like on farming, it takes us too long to garden. (P/079/FGD/37)

‘We are not free to go out. I just wish he was able to walk, I would be able to do what I want like, going to garden and work without disturbance. But now to do work while thinking about the child and the same time being poor at home, I lack peace’ (P/130/FGD/52)

On my part, I admire my friends doing big businesses (F. mmm) I think that if I do such businesses (F. mmm) who will stay with the child. He is a child that I just work while thinking about the child and the same time being poor at home, I lack peace’ (P/130/FGD/52)

We are not free to go out. I just wish he was able to walk, I would be able to do what I want like, going to garden and work without disturbance. But now to do work while thinking about the child and the same time being poor at home, I lack peace’ (P/130/FGD/52)

Table VI. Household poverty.

| Impact of childhood physical impairments in Malawi |

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‘We are not free to go out. I just wish he was able to walk, I would be able to do what I want like, going to garden and work without disturbance. But now to do work while thinking about the child and the same time being poor at home, I lack peace’ (P/130/FGD/52)

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Household poverty (11)

The primary aim of this study was to focus on the impact of MSIs in the lives of children. However, it soon emerged, through preliminary meetings with local stakeholders and then data collection, that the child's life could not be separated from that of the whole family.

Many parents and guardians spoke of being burdened in many ways. However, the burden that emerged as being most salient was the significant time that some parents – namely those of children with severe mobility impairments/dependency - lost to taking care of the child's basic needs (washing, feeding, toileting), escorting them to school/play, to hospital, and doing physiotherapy at home. Parents who carried their child with them to work (e.g. at garden plots) felt that they were slower and limited at work. This lost time was perceived as a real constraint on household productivity (Table VI). While some families had resources and/or found ways of coping with the lost time, others really felt the loss in household productivity in terms of poverty:

‘yes I look after the child, but I fail to harvest enough food. Because I spend time at the hospital whenever he swells, he swells in the months from January onwards …(…)…I do stay at the hospital until people harvest their produce, I stay in hospitals' (Parent/143/IDI/72)

Hunger (12)

Access to food and other basic needs were a challenge for many families, emerging time and time again in discussions. Against this backdrop of poverty, CMSIs were at a disadvantage in accessing food compared to able-bodied children in many ways (not shown). In particular, participation outside the home provided important opportunities for accessing food independently of their families. Children obtained food while playing (e.g. picking fruit, at friends’ homes) and at school (free daily meals at primary school). So children who were excluded from activities outside the home were at a significant disadvantage.

‘at least as for an able grown up person who goes to school, he knows that I will eat something at noon, while as a disabled person just stays at home the whole day [F. mm hh ] since he has been at home the whole day, that means he will need to eat … something yet you don’t have anything’ (Parent/061/FGD/28)

Some families were too poor to compensate for such inequalities within the home. Sometimes this was because they were restricted in household productivity by the MSI. The guardian who could not harvest enough food because of the months she spent in hospital with her child (above) went on to say she could not meet the child’s nutritional needs once at home. Another guardian who struggled to feed her 7 year child with MSI linked the food scarcity at home to the fact she could not work more because of the child:

‘when the food gets scarce [name] is concerned because she is mostly at home whilst her friends go out for playing, they get other food from some other people (F.mmm) while [name] cannot manage doing so…(…)…May be it’s because we have difficulties in walking because we cannot leave her at Mto lo…going to other people’s garden for cultivation in turn for cash/food’ (Parent/072/IDI/34).

Thus some CMSIs experienced the double disadvantage of being unable to access food both within and outside their home as a result of their disability.

Discussion

The model of impact

To our knowledge this paper is the first to give an in-depth, holistic view of the impact of MSIs in the lives of children in a low-income country in Africa, from the perspective of the children themselves, their families and communities. The model incorporates a key impact on the household (poverty) but is not comprehensive of all impacts on the family.

It should not be interpreted that all CMSIs and their families experienced indignity, exclusion, pain, household poverty and hunger. On the contrary, there was a lot of positivity in the day-to-day lives of CMSIs and their families, some seeming largely unaffected, especially if their MSI was visually and functionally invisible.
A key strength of the model is that it has been developed from a large set of empirical evidence about what is important in the lives of children with MSIs and how their lives are affected, ensuring its validity in the context of Malawi. It emerged from data without purposeful application of predefined theories or frameworks, yet strongly reflects the principles and articles of the UN CRPD (e.g. dignity, inclusion) and the WHO’S biopsychosocial model of disability (ICF) [1,23]. It also supports the recently published CBR guidelines, including the ‘CBR Matrix’, which calls for comprehensive action encompassing health as well as social protection, participation, recreation, employment and empowerment [7].

There is already international recognition for many of the themes and sub-themes in the model. Dignity is ‘a key construct in health, rights and disability and refers to the idea that all people have inherent (and equal) worth as human beings’ [24]. It is rightly a guiding principle of the CRPD, and there is evidence for individual sub-themes such as the mocking/bullying [25,26] and abuse of children with disabilities [27–29]. In relation to Exclusion, societal attitudes, behaviours and physical barriers (e.g. disability unfriendly infrastructure/transport) are internationally established targets for reducing the exclusion of PWDs. Pain is reported to be common across the comprehensive ICF Core Sets for 5 musculoskeletal and pain conditions [30]. Furthermore, it is well recognised that poverty is both a cause and consequence of disability and that households with severely immobile or dependent members (e.g. children with cerebral palsy) may become increasingly poor faced with ongoing direct (e.g. treatment) and indirect costs (e.g. lost productivity of caregivers) [31,32].

However, our model offers new and important insights, including a coherent theory of the possible relationships between the themes presented here. Firstly, diverse experiences of both social and physical barriers (being mocked/bullied, abused, left out, self care and toileting facilities/experiences) have been linked together as the common experience of indignity for the first time. This is progressive because despite dignity underpinning the CRPD and being put forward as outcome of rehabilitation, there is no operational definition of how to uphold Dignity in the lives of PWDs to which States can be held to account [32]. Consistent with others, this study easily identified violations of the Dignity (i.e. Indignity), rather than Dignity itself [33,34], suggesting tangible situations that must be targeted and evaluated to uphold Dignity. Empirical studies of dignity in relation to people - especially children - with disabilities are to date rare.

Secondly the model reveals outcomes of childhood MSIs that may be specific for CMSIs in this low-income setting. This includes the phenomena of families leaving CMSIs at home alone [35] and the exclusion of CMSIs in household chores such as fetching water, farming, cooking, cleaning. The former is associated with living with extreme day-to-day poverty, insecurity and inadequate social services and is not reported in studies of impact or coping among families with disabled children in high-income settings [36,37]. The latter is associated with the lifestyle and culture of living in poor, rural Africa. An independent qualitative study on child development in Malawi supports the importance of household chores as a social milestone in the lives of young children [38], consistent with expectations in Kenya [39].

Thirdly, the results of this study suggest that restricted household productivity is only part of the problem in the day to day hunger faced by children with severe mobility impairments, as they are additionally directly excluded from activities in which other children directly access food – independently of their families.

In the interest of communicating our findings using a common language we tried to link the model to the ICF-CY (Child and Youth version of ICF) [23]. However, many of the main themes (e.g. Indignity, Exclusion) are like the overarching concept of ‘Disability’ that is not categorised by the ICF but results from interactions between several of its components. Moreover, the categories to which the sub-themes can be linked do not provide the depth of analysis required. For example, the nearest category for both ‘Left Behind’ and ‘Let Down’ is ‘d498 Mobility, other specified’; for ‘Mocked and Bullied’ it is ‘e420 Attitudes of Friends’. The information lost in linking to the ICF-CY would defeat the very purpose of a study like this which is to fully understand a phenomenon from the local perspective so that one can plan and evaluate targeted interventions.

Limitations of the model include that despite being based on a wide range and severity of MSIs in Malawi, it may not be representative of children with all MSIs in all LMICs in Africa, including children with facial MSIs such as cleft lip/palate. Furthermore it does not distinguish differences in impact that may be important between girls and boys, children with congenital and acquired MSIs, and urban and rural children. The model is unlikely to capture the specific issues relevant to adolescent children with MSIs as this age group was not included in the study. The study is not able to report the extent to which the concepts are statistically representative of the population of CMSIs in Malawi; this should now be pursued through quantitative studies using probabilistic sampling methods. Lastly, the model focuses on current rather than long-term impact, and therefore does not include some concerns that guardians expressed about the future. In particular, they worried about what would happen to CMSIs once they (the guardians) died, wishing for them to be self-reliant.

Implications for practice and policy
The concepts of impact evidenced in the model demonstrate that the fundamental principles of the UN CRPD including ‘respect for inherent dignity’ and ‘inclusion’ of children with disabilities are not being upheld in Malawi [1]. Moreover children being ‘Abused’ and ‘Left Alone’ are violations of all children’s fundamental human rights. Interventions are urgently needed and this study provides comprehensive information on exactly what areas need to be targeted. As well as ‘health, employment, education and social services’ [6], legal structures are needed to ensure that the rights of CMSIs are upheld. Truly comprehensive, integrated and multifaceted interventions are needed to empower the lives of CMSIs and their families.

In planning interventions it is important to appreciate that Indignity affects children with visible MSIs regardless of the
site or severity of their impairment and this in turn is a major cause of Exclusion. Thus even a child with an apparently minor impairment (e.g. an extra toe) could experience Indignity and Exclusion. Children with all severities of impairment are therefore important targets of rehabilitation efforts.

Having said that, it is also important to recognise that children with severe mobility impairments and/or dependency (e.g. cerebral palsy) and their families are at risk of experiencing Indignity, Exclusion and Household Poverty and Hunger in more ways (e.g. humiliated/degraded, left alone, left behind) than children with less severe impairments. This is due to their dependency for self-care, restricted participation in activities away from home, and increased burden of care within the home. These children and families are particularly at risk and should be considered for prioritisation by rehabilitation and development programmes.

In particular, families facing dilemmas such as leaving their children home alone or going hungry need supportive interventions seeking to understand their real-life situations and provide feasible options, without casting blame or accusations of neglect. While interventions supplementing families’ basic needs might alleviate household poverty and hunger directly, there are many more benefits to those facilitating the participation of children in activities (play, school, household chores). The latter could alleviate household poverty and hunger in many indirect ways (liberating family members to undertake productive activities, direct contributions of CMSIs in doing productive work and in accessing food directly themselves) while at the same time reducing the Exclusion of CMSIs. This study supports the conclusion of others that a shift is needed from individual to family-centred rehabilitation [26,29].

Lastly, while emphasis on medical rehabilitation has been down-played in the disability movement in high-income populations, it is both needed and wanted in Malawi - to relieve pain and improve individual functioning so that CMSIs can participate in school, play, household chores, and are not dependent on their families now and in the long-term. The ability of CMSIs in doing individual activities (e.g. walking, moving, carrying, lifting, toileting, eating, writing) was intertwined in conversations as it was perceived to be pivotal for children going to school, playing and doing household chores, for the burden of care on families, and for children’s future self-reliance.

Implications for developing client-reported evaluation instruments

It is now widely accepted that patient-reported evidence is needed when evaluating the effectiveness of medical interventions [40]. Moreover, since the Global Centre for Development identified a major gap in evidence concerning the impact of social development interventions in the lives of target populations (2006), there is now increased pressure for all types of rehabilitation programmes to conduct high quality research leading to robust conclusions about the extent to which changes evidenced in the lives of clients can be attributed to an intervention [41]. This requires that valid and reliable instruments measuring client-centred outcomes (e.g. quality of life) are available in low-income contexts, for which very few (if any) are currently available for children with MSIs.

This study suggests that it is important that rehabilitation interventions for children with MSIs in LMICs such as Malawi are evaluated in terms of Exclusion (or Participation), Indignity (or Dignity), Pain, Household Poverty and Hunger. While the latter two may be accurately evaluated by objective assessments (e.g. household expenditure, weight/ arm circumference) [31,42], the first 3 concepts are clear candidates for subjective, questionnaire-based assessments by self or proxy report.

Our study suggests that new client-reported instruments need to be developed specifically for low income contexts rather than adapting existing instruments from high income countries. While pain, playing and participation at school are commonly assessed in existing outcomes questionnaires for children with and without disabilities, household chores and dignity are not. In a review of 21 international patient-based outcomes tools for children with MSIs, we found that only 3 asked about household chores [43].

Dignity has been measured mainly in relation to the care of the elderly and terminally ill adults and patient experiences of service delivery, but not in disability and rehabilitation [44–47]. This is despite being a fundamental principle of the CRPD and outcome of rehabilitation [1,32,48]. Sub-themes of Indignity have been included to a limited extent in some child-centred tools but they are not conceptualised around indignity nor covered comprehensively. For example, the PedsQL questionnaire has a single question on ‘getting teased by other children’, the KIDSCREEN has a Social Acceptance (bullying) subscale, and the DISABKIDS has a Social Exclusion subscale that includes questions on being left out and stared at [10,49,50]. Existing instruments are not comprehensive of the many different ways in which indignity arises as seen in this study.

The WHODAS 2.0 for adults has one question asking directly about dignity: ‘How much of a problem did you have living with dignity because of the attitudes and actions of others?’. It has been developed simultaneously across 19 countries including low-income countries in Africa (Nigeria) and Asia and Latin America. Adult instruments cannot be applied to children without careful and specific adaptation to this population and the developers of WHODAS 2.0 are exploring the development of a WHODAS for children and youth [51].

We conclude that development of new instruments such as a WHODAS for children with disabilities is indeed needed and hope that any development would be based on empirical evidence about children with disabilities in LMICs including the evidence presented in this paper.

Conclusion

The study highlights the need for implementing truly comprehensive rehabilitation services and developing new evaluation tools, both addressing the key issues of Indignity, Exclusion, Pain, Hunger and Household Poverty.

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