The impact of physical disabilities in the lives of young children in Malawi

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Childhood musculoskeletal impairments (MSIs)

**Conditions:**
- Clubfoot
- Bowlegs
- Burn contractures
- Extra digits/toes
- Spine deformities
- Arthritis
- Cerebral Palsy

**Interventions:**
- Surgery
- Drugs
- Assistive devices
- Physiotherapy
- Community-based rehabilitation

Article 26 – Rehabilitation:

‘States Parties shall take effective and appropriate measures…
to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services’
Problem

• Little evidence on impact of interventions

• No validated outcomes tools to measure impact

What concepts of outcome should be evaluated?
Study Aim

Develop a conceptual model representing the impact of MSIs in the lives of children aged 2-10 yrs in Malawi
Methods

Qualitative Study:

- 169 participants
- 57 in-depth interviews, focus groups, observations
- Systematic & purposive sampling - site/severity of MSI, age, gender, urban/rural, intervention status, schooling
## Methods

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>In-depth Interview</th>
<th>Focus Group</th>
<th>Observation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children with MSIs (2-5 yrs)</td>
<td>8</td>
<td></td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Children with MSIs (6-10 yrs)</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Siblings</td>
<td>9</td>
<td>3</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>Parents/guardians</td>
<td>10</td>
<td>8</td>
<td></td>
<td>18</td>
</tr>
<tr>
<td>Adults with MSIs</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Teachers</td>
<td>2</td>
<td>1</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Health Workers</td>
<td>2</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Community Leaders</td>
<td>2</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>26</strong></td>
<td><strong>21</strong></td>
<td><strong>10</strong></td>
<td><strong>57</strong></td>
</tr>
</tbody>
</table>
Methods

Qualitative analysis:

• Transcribed verbatim (Chichewa) → translated (English)
• Data-led analysis
• Multiple stages of coding and grouping codes
• Themes – conceptualisation of impact
• Sub-themes – conceptualisation of different ways in which impact arose
Results
Conceptual model: Impact of MSIs in the lives of children in Malawi

HOUSEHOLD POVERTY

PAIN

HUNGER

EXCLUSION

INDIGNITY

Let down (physically)

Left behind (physically)

Left alone

Left out (overprotected, discriminated)

Mocked & bullied

Abused

Humiliated & Degraded

Withdrawing & abstaining
Indignity

- Left out (overprotected, discriminated)
- Mocked & bullied
- Abused
- Humiliated & Degraded
“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)
Indignity

- Left Out (overprotection, discrimination)
- Mocked & Bullied
- Abused
- Humiliated & Degraded
Indignity

- Left Out (overprotection, discrimination)
- Mocked & Bullied (by peers)
- Abused
- Humiliated & Degraded

“they would throw stones at her and insult her while she is just sitting on the verandah so she starts crying”

(Parent/118/IDI/71)
Indignity

- Left Out (overprotection, discrimination)
- Mocked & Bullied (by peers)
- Abused (physical & verbal - by adults)
- Humiliated & Degraded

“we parents know that these disabled children do not do things normally, and we end up taking a stick and whipping them.”

(Parent/128/FGD/52)
Indignity

- Left Out
- Mocked & Bullied
- Abused
- Humiliated & Degraded

“…if an able bodied person like me, walking, is failing to properly use the toilet but just urinating at the door. Then how will someone get off a wheelchair when the urine is just dripping all over the place”.

(Teacher/001/IDI/1)

(dependency for self-care, use pit latrines)
Indignity

Left out (overprotected, discriminated)
Mocked & bullied
Abused
Humiliated & Degraded

INDIGNITY
Exclusion

- Let down (physically)
- Left behind (physically)
- Left alone
- Left out (overprotected, discriminated)

Withdrawal & abstaining
Exclusion from Participation in School, Play & Household Work
Exclusion from Participation in School, Play & Household Work

- Withdrawing & Abstaining
- Let Down
- Left Behind
- Left Alone
- Left Out
Exclusion from Participation in School, Play & Household Work

- Withdrawing & Abstaining (to avoid indignity)
- Let Down
- Left Behind
- Left Alone
- Left Out

...there was a group of people at the borehole laughing at me that the disabled…(...)…I would just turn back without reporting again for two years, I have failed at school just repeating STD1, failing to continue because of people were laughing at me

(Adult with MSI/033/FGD/09)
Exclusion from Participation in School, Play & Household Work

• Withdrawing & Abstaining (to avoid indignity)

• Let Down (physically by their bodies)

• Left Behind (physically due to long distances)

• Left Alone (at home without proper supervision)

• Left Out
  (overprotected, discriminated)
Exclusion from Participation in School, Play & Household Work

- Withdrawing & Abstaining
- Let Down
- Left Behind
- Left Alone
- Left Out (overprotected, discriminated)

“But my child in the end said why do you discriminate me? …that the child should not do any work because of having an impairment…like sweeping like he was saying, cooking because we would say the food would not be well prepared, because of having an impairment that the child should not wash plates” (CL/026/FGD/10)
Exclusion

- Let down (physically)
- Left behind (physically)
- Left alone
- Left out (overprotected, discriminated)

Withdrawal & abstaining
Conceptual model: Impact of MSIs in the lives of children in Malawi

EXCLUSION

INDIGNITY

- Let down (physically)
- Left behind (physically)
- Left alone
- Left out (overprotected, discriminated)
- Mocked & bullied
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Withdrawing & abstaining
Pain

HOUSEHOLD POVERTY

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EXCLUSION

INDIGNITY

Let down (physically)
Left behind (physically)
Left alone
Left out (overprotected, discriminated)
Mocked & bullied
Abused
Humiliated & Degraded

Withdrawing & abstaining
“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”

(Child with MSI/119/IDI/51)
Impact of MSIs in the lives of children in Malawi
Household Poverty & Hunger

- Excluded from opportunities to access food

+ Reduced Household Productivity

“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 while [name] cannot manage doing so…(...)

May be it’s because we have difficulties in walking because we cannot leave her at Mtolo…going to other people’s garden for cultivation in turn for cash/food”

(Parent/072/IDI/34)
Impact of MSIs in the lives of children in Malawi

- Household Poverty
  - Pain
  - Hunger
  - Exclusion
    - Left down (physically)
    - Left behind (physically)
    - Left alone
    - Left out (overprotected, discriminated)
    - Mocked & bullied
    - Abused
    - Humiliated & Degraded
    - Withdrawing & abstaining

- Indignity
Conclusion
Impact of MSIs in Malawi

• **Indignity** (Affront to sense of human worth)

• **Exclusion** (School, Play, Housework)

• **Pain**

• **Household Poverty & Hunger**
Way forward?

• Multifaceted interventions needed at all levels
  - Child, family, community

• Tools to evaluate impact of rehabilitation:
  - New tool(s) needed to evaluate Exclusion/Indignity
  - Children with MSIs vs. all disabilities?
  - Malawi vs. low-income countries?
International Collaborative Team

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