

Experiences of caregivers of children with spastic cerebral palsy regarding splinting in Uganda

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Cerebral palsy

- Most common childhood motor disability
- Spasticity:
 - Movement is difficult
 - Muscles are tight
 - Joints have contractures & become deformed
- Splints:
 - Help reduce spasticity
 - Help keep limbs straight
 - Improve function

Problem in Uganda

- Children with cerebral palsy are provided with splints
BUT
- They come back to hospital with contractures & deformities

Aim of study

- Describe & understand caregivers' experiences regarding splinting

Methodology

- Qualitative exploratory research design
- 2 research settings in Uganda
- 24 caregivers
- In-depth interviews
 - Interviews in Luganda (language) in caregivers' homes
 - Audio-taped, transcribed, translated into English, analysed
- Ethical issues considered (informed, written consent)

Findings: Demographic profile of caregivers & children

- 24 caregivers
 - 21 mothers
 - 1 father
 - 2 grandmothers
- 24 children aged 3-17 years

Children's diagnosis	Number of children
Spastic hemiplegia: 1 arm & 1 leg affected	10
Spastic quadriplegia: Both arms & legs affected	11
Spastic diplegia: Both legs affected	3

Theme 1: Caregivers' expectations and beliefs about the splint

- Child will be healed, cured or become 'normal'
"I believe it will heal my child because those [mothers] I started with, their children are better than mine. I expect my child to get well." (Child 7 years)
- After improvement, caregivers did not expect further change

Theme 2: Acquiring splints

- Caregivers & children not included in decision making
- Time:
 - Usually took 1-3 weeks to make splint
 - Sometimes required repeated visits to health facility
 - Travelling time difficult
- Costs:
 - Cost of splint
 - Transport cost high

“What I have observed is that the splints are expensive. We pay for them, it is so costly. It cuts into our income.” (Caregiver)

Theme 3: Caregivers' knowledge of & skills applying splints

- Information from therapists and orthotists
- Children have little understanding of splints
- Caregivers & children not involved in making decisions
- Taught about precautions
- *“I was told that before I splint him, I had to dress him in socks then straighten the legs then apply the splint.”* (Child 10 years)

Theme 4: Attitudes to splints

1. Caregivers attitudes: positive – splints beneficial & necessary
2. Children's attitudes: did not like their splints

“He cries; he doesn't like the splint especially when I try straightening his legs. He does not like the splints.” (Child 11 years)

Theme 4: Attitudes to splints

3. Community members attitude:

- Some like & help the child
- Some fear the child
- Some ridicule the child

“During school time I think other students disturb or bully him because he comes back home when he has put the splint in the bag.” (Child 7 years)

- Negative attitude of neighbours & their children decreased use of splints
- Older children then removed their own splints

Theme 5: Compliance using splints

“I like the splint but I do not know how to make the child like it too; because fellow children laugh at her so much when she wears it then she removes it.” (Child 11 years)

- Challenges:
 - Splint not fitting – causes pain & discomfort
 - Child cries, removes splint,
 - Splint prevents doing activity
 - Time-consuming putting on splint for caregiver
 - Costs of splint (unless given financial assistance)
 - Travelling difficult
 - Difficult to find carer for other children when travelling

Theme 6: Benefits experienced

1. Impairment:

- Reduced spasticity
- Increased mobility
- Limb straighter

2. Activity limitation:

- Improved function e.g. walking

3. Participation Restriction

- Improved participation

“The foot was initially very deformed but now it is straightened although the child walks with a limp.

The child can also play more than before. The child can also dress independently.” (Child 9 years)

Conclusion

Factors influencing use of splints & recommendations:

- Caregivers' having positive expectations
- Child's age & understanding
 - Include caregivers & children in making decisions
- Caregivers', children's and community members's attitudes to the splint
- Comfortable fit of splint
 - CBR workers need to give support in community
- Costs:
 - splint & transport
 - information on financial assistance



Thank you!!

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