

caregiver what the importance of the splint is and the expected outcome from splinting. This would help the caregiver to have realistic expectations from the splints for their particular child.

The physiotherapist needs to specifically explain to the caregivers the reason for the splint, what to expect from the child using the splint, as well as suggest the possible outcomes of the child using the splint. This may in effect encourage the caregivers to assist the child to adhere to use of the splint if the caregivers understand the importance of splinting.

5.8 Limitations of the study

This study has the following limitations, which need to be taken into consideration when interpreting the findings:

1. There was no data triangulation as only one method of data collection in-depth interviews was used. A second method such as a focus group discussion with some of the caregivers may have confirmed the findings of the interviews or resulted in different data.
2. The researcher could have gone back to each participant with a transcript and either read it to the participant or given it to the participant to read to see if the person agreed with what was written.
3. There was a very small number of male participants (n=1). This is not surprising in Uganda where most care giving is by women. However, it is recognized that male and female caregivers may have different perspectives and this was not explored in this study.
4. The sample selected was caregivers of a heterogeneous group of children with wide range of age ranges, diagnosis and severity. Additionally there was a diverse group of caregivers. This was intended and allowed for a very wide range of experiences of caregivers to emerge in the data. However, it is not possible group the caregivers or the children into clusters or to make comparisons which may be possible if the children were in a more homogeneous group, for example, according to age, diagnosis and gross motor function scale level.
5. The researcher (a physiotherapist) may have unknowingly had prior interactions with some of the families. This may have created an inherent bias toward the caregivers providing positive feedback about service providers, especially rehabilitation therapists.

Summary

The results in this study present the overwhelming challenges caregivers face while splinting children with CP. The caregivers struggle with applying the splints even when they know they cause the child discomfort or pain or even sores. The results highlight the need, when considering splinting, to take into account the personal (child) factors, splint characteristics and environmental (family and community) factors. They also demonstrate the importance of taking children's different developmental stages, such as age, and unique personal experiences into consideration when recommending splinting for children with CP.

The data from qualitative methodology is not intended to be generalizable. However, the insights from the experiences shared frequently are, as can be seen in the similarities to other studies. However, the context is always an important factor and so the findings may be different elsewhere in Uganda or in another country if the context is different.



CHAPTER SIX: SUMMARY, CONCLUSION, SIGNIFICANCE AND RECOMMENDATIONS

Introduction

This chapter provides the summary, conclusion, significance of the study as well as recommendations to improve service provision of splints and adherence to splinting.

6.1 SUMMARY

CP is a motor disorder caused by damage to a developing brain. The spastic type of CP is the most common and disabling type especially if the distribution involves all limbs. Spasticity is a major characteristic and cause of contractures in children with CP. There is evidence to indicate that sustained stretching using splinting can improve range of movements, reduce spasticity of targeted joints, or to facilitate function and can be used as a long term measure to prevent contractures from forming or recurring by stretching the spastic muscles. However, some children with CP in Uganda who have been issued with splints return to the physiotherapy department with contractures or deformities. It was not known why this has happened and many therapists assume it is because splints are not used at home as prescribed. Hence, there was a need to explore what caregivers' experience during the splinting process at home.

The theoretical framework used in this study was the bio-psychosocial model of disability and the International Classification of Functioning, Disability and Health (ICF). The ICF was used in this study to understand the social forces or relations that affect the child during the splinting process. The biological aspect of the model was used to understand the impact of the child's impairment on the splinting process. The aim of this study was to describe the caregivers' experiences regarding splinting so as to understand what factors affect adherence to splinting instructions.

Although there are a number of systematic review articles of randomised controlled trials on the effectiveness of stretch in CP, there are none on splinting. However, there is evidence that splinting can improve range of movement, reduce spasticity of targeted muscles and improve function as well as prevent contractures and deformities in children with spasticity in CP. There is also evidence that caregivers are influential in deciding whether children use splints or not, and that there are environmental or personal factors that affect adherence to splinting. Literature also recommends that therapists need to understand the reasons behind use and

non-use of splints so as to promote adherence. Personal factors identified from literature included: compliance by the child and dedication of parents, as well as the age and development of child. The environmental factors included: approach used by therapist, parents' perception of splinting and understanding and belief of caregivers about reasons for splinting.

A qualitative exploratory research design methodology employing in-depth interviews was selected for the study. Two centres were used for data collection. 24 caregivers who had met the specified selection criteria participated. Appropriate ethical issues were considered to gain access to the centres and to maintain confidentiality of the caregivers. The data was analysed using content analysis.

The six themes identified were: Caregivers' expectations and beliefs; Acquisition of splints; Knowledge and skills; Attitudes to splinting; Compliance and Benefits of splinting. Caregivers' expectations included the child getting healed, the splint causing a change in the child's limb or no improvement. The change in the limb could be straightening the limb, relaxing the muscles or improvement in function. Some caregivers who had already experienced an improvement did not have any more expectations from splinting. Some caregivers believed that the outcome of splinting was dependent on divine intervention and other related it to treatment by traditional bone setters. Caregivers reported that it took a period of between one to three weeks to obtain the splint. However, at times the splint was not ready and the caregivers had to return several times before the child got fitted.

Caregivers stated that the splinting process could be very time-consuming. They stated that the costs involved in splinting were high unless they got support from an outside organisation. These costs included the cost of the splint, transport and the time off work. Caregivers explained that they were taught how to apply the splints on the date of fitting by the therapist or the orthopaedic technician. Caregivers were taught skills but did not all feel sufficiently informed about the splinting process. They were taught exercises, how to ensure function. Some caregivers reported that some of the children were included in the discussions with the Physiotherapists. Caregivers reported that they learnt what to do when the child cried with the splints, when to go for replacement, hygiene and splinting precautions. The attitudes of most caregivers were positive and that splinting was good. The attitude of many of the children was that they did not like the splints as they caused pain or discomfort. Other children felt stigmatised because of the splints. Other children and neighbours reacted in

different ways to the child wearing the splints; some liked the child while others feared the child, others helped the child to use the splints while others ridiculed the child.

Regarding compliance with use of the splint, most caregivers mentioned that children needed assistance to apply the splint, while a few children could apply their own splints. Some caregivers mentioned precautions taken before applying the splint including exercises, correct positioning and wearing a protective sock. Some caregivers mentioned that they find it difficult to trust anyone else to do this. Most caregivers splint either during day or night time and a few both day and night. The caregivers mentioned the challenges experienced during splinting that affect compliance. These included the splint not fitting, crying, pain or discomfort, the child removing the splint, the difficulty applying the splint when there was a lot of spasticity, illness, difficulty with transport, difficulty leaving the other children at home when going to the centre, ulceration, and excessive warmth. Caregivers described the benefits from splinting including reduced spasticity, increase in joint mobility, apparent improved strength, and improved function. The caregivers also suggested solutions to some of the challenges including the use of hinged splints, dynamic splints, boots, and lightweight splints.

The results in this study present the overwhelming challenges caregivers face while splinting children with CP. The caregivers struggle with applying the splints even when they know they cause the child discomfort or pain or even sores. The results highlight the need, when considering splinting, to take into account the personal (child) factors, splint characteristics and environmental (family and community) factors. They also demonstrate the importance of taking children's different developmental stages, such as age, and unique personal experiences into consideration when recommending splinting for children with CP.

The results in this study are not intended to be generalizable. However, the insights from the experiences shared frequently are, as can be seen in the similarities to other studies. However, the context is always an important factor and so the findings may be different elsewhere in Uganda or in another country if the context is different, for example if all splinting and transport for splinting is free. Where the context is similar it is very possible that the findings will also be similar.

6.2 Conclusion:

The purpose of this study was to describe the caregivers' experiences of caregivers of children with spastic CP regarding splinting in Uganda. The results indicate that caregivers face overwhelming challenges during the period their children wear splints. The results

highlight the need, when considering splinting, to take into account the personal (child) factors, splint characteristics and environmental (family and community) factors. The factors linked to the child include age, attitude towards splinting and impairments. The factors linked to the splint include cost of the splint, comfort ability and duration of use of the splint. The factors linked to the family include caregiver's beliefs, expectations, knowledge and skills as well as attitudes towards splinting. The factors linked to the community include community attitudes towards splinting.

The findings in this study show that caregivers experience positive as well as negative experiences while assisting the child with the splinting process. Positive experiences may be as a result of the splint causing an improvement in the child's impairment, activity limitation or community participation. On the other hand, negative experiences may occur as a result of splint specifications, for example if the splint is too tight and makes the child uncomfortable, cry or causes the child sores. Other negative experiences may be attributed to the attitudes of people towards the child using the splint such as stigmatisation.

Recommendations include involving caregivers and at times the child in the discussion about splint prescription, as well as providing information on splints to children with CP and their families. Another recommendation is that follow-up and continuous evaluation of splint usage is needed so as to improve utilisation of splints by caregivers and children with CP.

6.3 SIGNIFICANCE

This study will contribute to the literature that focuses on splinting for children with CP in Uganda. The findings in this study may be useful to Physiotherapists as a source of information about experiences caregivers are likely to go through during the splinting process. This may change the way that the physiotherapists have been prescribing splints as the findings in this study emphasise the importance of involving the caregivers and child during the prescription of splints. In Uganda, this is not common practice even though literature recommends this type of client-centred practice.

6.4 RECOMMENDATIONS

There are a number of recommendations based on the findings of the study.

6.4.1 Provide caregivers with information

More information on splints should be provided to both children with CP and their caregivers BY PHYSIOTHERAPISTS. Information should include the reasons for using splints, the

benefits from splints, the possible challenges and how to address these difficulties while at home. This information can be provided in a printed booklet, an example is attached (Appendix F) for the caregivers to take home. The booklet may have sections for physiotherapists and caregivers and the child. For the physiotherapists, the booklet may include a checklist for them to ensure they have covered all the areas needed when discussing with the caregiver and child regarding the splinting process. The information in this booklet may include the reasons for issuing the child the splint, how caregivers can apply the splint, when to apply the splint, for how long and how to address challenges they may face. The booklet may also include a telephone contact that the caregivers can use to inform the physiotherapists in case of challenges. This is considered a cheaper option compared to the caregivers having to travel to the service provider.

6.4.2 Involve caregivers and children in decision making

Compliance could improve if physiotherapists would involve caregivers and where possible the children in deciding if a child would benefit from using a splint. The discussion physiotherapists need to have with caregivers and at times children before they recommend or prescribe splints will include the costs of the splints, the cosmetic appearance of splints, splint type and durability as well as children's individual differences and what functional outcomes are expected from splinting.

6.4.3 Follow-up and evaluation

On-going support by community based rehabilitation workers is needed at home. These workers can monitor splint usage at home perhaps on a monthly basis and give updated reports to the physiotherapists. Follow-up and continuous evaluation of splint usage is needed for the children and their caregivers; in order to better match the children's needs, and improve their knowledge to deal with the difficulties that they face in their daily splint use. Hence, therapists at the service providers need to ensure that they discuss with the caregivers and at times the children the challenges they may be facing while at home. In addition, the way in which the therapist will initiate follow up with the child and caregiver needs to be explained when the splint is issued. It needs to be part of the job description of community based rehabilitation workers to check up on splint usage at home. It is also important there is two ways communication from caregivers to physiotherapists as well as from physiotherapists to caregivers and children, through the community based rehabilitation worker. This will improve on the communication between the institution's therapists and caregivers especially for families from outlying/ remote areas.

6.4.4 Service providers

Training related to effective communication is needed for therapists; this training should include listening skills in order to understand caregiver and child expectations, explaining medical issues or procedures to caregiver/ child.

During splint production, it is vital to consider factors such as comfort and child's individual needs. If the splint is to be worn daily, it should be worn at a time that does not prevent clients, namely the caregiver and the child, from participating in social activities. Management at the service providers should put in place measures to ensure splints are produced when promised and that the splints are of good quality.

6.4.5 Further research

The researcher recommends research on the new information booklet that is given to caregivers to check if it is helpful and what needs to be improved. Research may also be carried out on what information different community institutions need so that stigmatization is reduced, such as what information schools need so that teachers can help with stigma reduction. Research may also be conducted to find out how costs could be reduced. The findings from these studies could be used for proposing strategies for improving of splinting interventions for children with CP in Uganda.

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APPENDIX A: INFORMATION SHEET



UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959, Fax: 27 21-959

E-mail: xtinetussy@gmail.com

Project Title: EXPERIENCES OF CAREGIVERS OF CHILDREN WITH SPASTIC CEREBRAL PALSY REGARDING SPLINTING IN UGANDA

What is this study about?

This is a research project being conducted by Christine Tusime a student at the University of the Western Cape in South Africa. We are inviting you to participate in this research project because you are a caregiver of a child with cerebral palsy (CP) who received a splint in 2010. The purpose of this research project is to inform therapists of the experiences of caregivers regarding the splinting process so as to improve service delivery.

What will I be asked to do if I agree to participate?

You will be asked to participate in an interview at either CoRSU Rehabilitation Hospital or at Katalamwa Cheshire Home (KCH). Topics in the discussion will be concerned with your knowledge of and experiences during the splinting process. The interviews will last between 60 to 90 minutes.

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. 1) To help protect your confidentiality, all information gathered will be kept in locked cabinets that can only be accessed by the researcher. 2) All your responses will be coded so no link to your identity will be made when reporting the findings. 3) If we write a report or article about this research project, your identity will be protected to the maximum extent possible. 4) In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others.

This research project involves making audiotapes of the interview. The tapes are being made so as to enable the researcher to accurately capture the information. The researcher, a translator and transcriber will have access to the tapes. The tapes will be locked in a cabinet that can be assessed only by the researcher. The tapes can be destroyed six months after the research project.

___ I agree to audiotaped during my participation in this study.

___ I do not agree to be audiotaped during my participation in this study.

What are the risks of this research?

There are no known risks associated with participating in this research project.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about what factors are associated with splinting process. We hope that, in the future, other people might benefit from this study through improved understanding of the splinting process. The results of this study will be used to make recommendations on how to make it easier to use splints when at home. The information will also be used to inform therapists what information caregivers need to assist them with splinting the children when at home. This will hopefully save many children from pain that is caused as a result of stiffness and deformities from not using the splints. By preventing stiffness and deformities we will hopefully reduce on health care costs for the families of these children.

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized and it will not affect your child's therapy services.

What if I have questions?

This research is being conducted by Christine Tusiime a student at Physiotherapy Department at the University of the Western Cape. If you have any questions about the research study itself, please contact Christine Tusiime at CoRSU, P.O box 16548, Kisubi, Uganda. Tel: +256702266976. Email: xtinetussy@yahoo.com

Should you have any further questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department: Prof. Julie Phillips
Dean of the Faculty of Community and Health Sciences: Prof. Mpofu
University of the Western Cape
Private Bag X17
Bellville 7535

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

APPENDIX B: CONSENT FORM



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959, Fax: 27 21-959

E-mail: xtinetussy@gmail.com

Title of Research Project: EXPERIENCES OF CAREGIVERS OF CHILDREN WITH SPASTIC CEREBRAL PALSY IN UGANDA

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name.....

Participant's signature.....

Witness.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Christine Tusiime

CoRSU Rehabilitation Hospital and Rehabilitation Centre

P.O. Box 46, Kisubi.

Uganda

Email: xtinetussy@gmail.com

APPENDIX C: INTERVIEW GUIDE

EXPERIENCES OF CAREGIVERS OF CHILDREN WITH SPASTIC CEREBRAL PALSY REGARDING SPLINTING

Background:

Set the interviewee at ease: explain purpose of interview.

➤ Researcher introduces self to the caregiver, explains the purpose and importance of caregivers' participation in the study and assures them of anonymity, and confidentiality.

Question: Tell me about your experiences during splinting.

Probes:

1. Can you give examples of positive or negative experiences?
2. What are your opinions about splinting? Why?
3. What are your beliefs about splinting? Why?
4. Describe how you splint (splinted) your child.
5. Any challenges you have (had) with using the splint?
6. How do you manage the difficulties or challenges experienced?
7. What were your expectations of using the splint? Why?
8. Any other information related to splinting in this facility would you like us to talk about?

Thank you!!

APPENDIX D: DEMOGRAPHIC QUESTIONNAIRE

Attendant's name:

Relationship to child:

Child's Name:

Child's Age: _____

Sex: _____

Diagnosis:

Name(s) / Type(s) of splint:

Reason(s) for splint:

BACKGROUND: (family conditions, social history, source of income)



APPENDIX E: Table 4.1 Demographic profile of participants and children

Participant		Child			Splint		Family Social information
	Relation to child*	Age * (yrs.)	Sex	Type of CP**	Type of splint**	Reason for splint**	
Cg A	Grandmother	7	Male	Spastic hemiplegia	Wrist (extension) cock-up splint	Prevent contracture left wrist	Child stays with grandmother and 11 other children. Grandmother's source of income is working on other people's farms.
Cg B	Mother	6	Male	Spastic quadriplegia	KAFOs	Prevent contractures of bilateral knees and feet	Child stays with both parents and is the 3 rd born in a family of 3 children. Father is a carpenter and mother is a housewife.
Cg C	Mother	11	Male	Spastic quadriplegia	KAFOs	Prevent contractures of bilateral knees and feet	Child stays with both parents and is the 6 th born in a family of 9 children. Mother is a house wife and father is a brick maker nearby home. One of the younger sister's also has cerebral palsy.
Cg D	Father	4	Female	Spastic hemiplegia	Wrist and hand splint	Prevent contracture of left hand	Child stays with both parents and is the 1 st born of 2 children. Both parents are shop attendants.
Cg E	Mother	7	Male	Spastic hemiplegia	Wrist and hand splint	Prevent contracture of left hand	Child stays with both parents and is the 4 th born of 6 children. Father is a store manager and mother is a waitress in a restaurant.
Cg F	Mother	9	Male	Spastic hemiplegia	AFO	Prevent deformities right ankle and foot	Child stays with single mother and is the 3 rd born of 4 children. Mother works in a laundry mart.

Cg G	Mother	7	Male	Spastic hemiplegia	AFO	Prevent deformities left ankle and foot	Child stays with both parents and is the 3 rd born of 5 children. Mother is a peasant farmer, father is a business man.
Cg H	Mother	11	Female	Spastic hemiparesis	Hand splint	Straighten fingers of left hand	Child stays with single mother and is the 5 th of 6 children. Father abandoned the children and their mother. The family stays with the mother's parents. The mother is a casual labourer and her parents are peasant farmers.
Cg I	Mother	11	Female	Spastic quadriplegia	KAFOs	Prevent deformities both knees and feet	Child stays with both parents and is the 1 st born of 3 children. Has a sister and brother with CP.
Cg J	Mother	8	Female	Spastic quadriplegia	KAFOs	Prevent contractures both knees and feet	Child stays with both parents and is the 2 nd born of 4 children. Father is a peasant farmer and mother is a housewife.
Cg K	Mother	4	Male	Spastic hemiplegia	AFO	Prevent contractures right ankle and foot	Child stays with both parents. Child is the only child. Father works at a fuel station and mother is a housewife.
Cg L	Grandmother	4	Male	Spastic diplegia	AFOs	Prevent contractures both ankles and feet	Child stays with grandmother. Child is an only child. Grandmother gets income from 5 single rooms that she rents to people.
Cg M	Mother	12	Male	Spastic diplegia	KAFOs	Reduce spasticity both knees, ankles and feet	Child stays with both parents. He is the 1 st born of 4 children. Father works in public transport and mother is a primary school teacher.
Cg N	Mother	17	Male	Spastic hemiplegia	Wrist splint	Prevent contractures right wrist	Child stays with single mother and is the 3 rd born of 6 children. The mother is

							employed in a laundry mart.
Cg O	Mother	17	Male	Spastic hemiplegia	Wrist splint and AFO	Reduce spasticity right wrist, ankle and foot	Child stays with both parents and is the 4 th born of 6 children. The father is a driver and the mother is a house wife.
Cg P	Mother	15	Male	Spastic hemiplegia	Wrist splint and AFO	Reduce spasticity left wrist, ankle and foot	Child stays with both parents and is the 5 th born of 5 children. The father is a builder (construction worker) and the mother is a house wife.
Cg Q	Mother	10	Female	Spastic quadriplegia	Wrist splints and AFOs	Prevent deformities both wrists and ankles	Child stays with both parents and is the 4 th born of 4 children. The father is a driver and the mother is a shop attendant.
Cg R	Mother	9	Female	Spastic athetoid quadriplegia	Wrist splints and AFOs	Provide stability both wrists and ankles	Child stays with both parents and is the 4 th born of 6 children. Both parents are peasant farmers.
Cg S	Mother	6	Male	Spastic athetoid quadriplegia	AFOs	Provide stability both feet	Child stays with both parents and is the 1 st born of 2 children. Both parents are peasant farmers.
Cg T	Mother	10	Female	Spastic diplegia	KAFOs and AFOs	KAFOs (reduce spasticity) AFOs (prevent contractures both ankles)	Child stays with both parents and is the 6 th born of 6 children. Both parents are peasant farmers.
Cg U	Mother	5	Female	Spastic quadriplegia	KAFOs and AFOs	KAFOs (reduce spasticity) AFOs (prevent contractures both ankles)	Child stays with both parents and is the 4 th born of 6 children. Father is a peasant farmer. Mother is a house wife.
Cg V	Mother	10	Male	Spastic quadriplegia	Wrist and hand splints and	Prevent deformities of hands, wrists and lower limbs	Child stays with both parents and is the 4 th born of 4 children. Father is a peasant

					KAFOs		farmer. Mother is a house wife.
Cg W	Mother	3	Male	Spastic quadriplegia	Wrist and hand splints and KAFOs	Prevent contractures bilateral wrists, knees and ankles	Child stays with both parents and is the 4 th born of 7 children. Father is a businessman. Mother is a house wife.
Cg X	Mother	5	Male	Spastic quadriplegia	Wrist and hand splints and KAFOs	Prevent contractures bilateral wrists, knees and ankles	Child stays with both parents and is the 1 st born of 4 children. Father is a builder. Mother is a house wife.

Key:

* Information from the caregiver

** Information from child's file

AFO – Ankle Foot Orthosis

KAFO – Knee, Ankle, Foot Orthosis



APPENDIX F: CAREGIVER SPLINTING INSTRUCTIONS BOOKLET

Introduction

The information in this booklet has been compiled to help caregivers during the time their child will be using a splint to help reduce spasticity. Spasticity in children with cerebral palsy is very common but often difficult to treat. Spasticity is considered a problem when it interferes with activities such as movement, hygiene, or positioning. There are numerous ways to treat spasticity, splinting is just one of the treatment options.

GENERAL INFORMATION ABOUT SPASTICITY

What is spasticity?

Spasticity is muscle stiffness that causes the child to resist movement.

Types of spasticity

Spasticity varies from mild muscle stiffness to severe.

Areas affected by spasticity

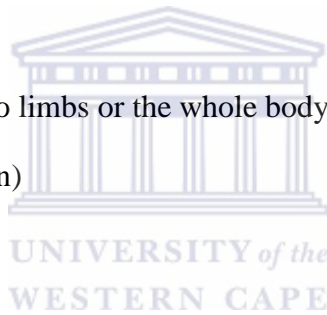
Spasticity can affect one limb, two limbs or the whole body.

Symptoms of spasticity (common)

- increased muscle tone
- rapid muscle contractions
- exaggerated deep tendon reflexes
- muscle spasms
- scissoring (involuntary crossing) of the legs

Other symptoms (not so common)

- pain,
- loss of range of joint movement, or contracture (continuous tightening of joint that restricts normal movement).
- skin breakdown, broken bones and sleep disorders. It can limit many activities of daily living and the delivery of care.



SECTION A: DEMOGRAPHIC INFORMATION

Name of patient:

Age: _____

Type of splint(s):

Reason for splint(s):

Impairments (of body function and structure):

Activity limitations and Participation restrictions:

Environmental factors (physical, social and attitudinal environment in which people live and conduct their lives):



SECTION B: THERAPIST CHECK LIST

Date of measurement for splint_____ Date of fitting splint_____

1) Type of splint (tick all applicable)

- ☐ Hand splint ☐ Elbow splint ☐ AFO ☐ KAFO
☐ Other _____

2) Reason for splinting (tick all applicable)

- ☐ prevent contracture/ deformity ☐ keep the joint in the functional position
☐ stabilize the limb joints ☐ facilitate motor control
☐ decrease spasticity

3) Expected functional outcome _____

4) Whom prescription of splint has been discussed with (tick all applicable)

- ☐ caregiver ☐ child ☐ doctor ☐ community based rehabilitation worker
☐ social worker ☐ other _____

5) Is splint padded? ☐ YES ☐ NO

6) Is splint comfortable for child? ☐ YES ☐ NO

If no, return to workshop for modification.

7) Discussed possible challenges ☐ YES ☐ NO

8) Discussed follow-up plan ☐ YES ☐ NO

9) Expected duration of using splint _____

10) Review plan

- ☐ Weekly ☐ Monthly ☐ Every 2 months ☐ Every 3 months

Other comments

SECTION C: CAREGIVER SPLINT INSTRUCTIONS

Introduction

There are a variety of splints made from a number of different materials. The splint prescribed depends on a child's impairments. The splint is meant to be comfortable. If areas of the skin become red, this indicates that the splint may not be fitting appropriately, especially if the redness lasts more than 20 minutes after removing the splint.

SPLINT INSTRUCTIONS

1) Precautions

- Upon receiving the splint, splint the child for _____ minutes. Take it off and check the skin area for: redness, swelling or pain that persists more than 20 minutes. If no problems were present after wearing the splint, then continue to wear splint as instructed. If problem was noted call the therapist and inform them of the problem.
- For the first 3- 5 days after receiving the splint, the splinted limb may need to be raised up on pillows or a wedge while in bed or when sitting to prevent swelling.
- If the splint causes any of these problems during splinting process, remove it and call the therapist:
 - Pressure area (sores, blisters or red marks) that do not go away within one hour after removing the splint
 - Increased swelling
 - Excessive stiffness, pain or numbness
- Keep the splint away from heat, open flames or prolonged sunlight because it may get heated up and lose shape.

2) Caregivers expectation from splinting

When child should wear splint (follow the direction that is checked)

- ☐ Always wear the splint
- ☐ Wear the splint at night and during rest periods only
- ☐ Wear the splint during the daytime only

Always remove to exercise and bathe the child

3) How to apply the splint

- ✓ Check the skin and ensure it is free from sores, blisters or rash
- ✓ Check the splint and ensure it is dry and has no sharp points or object inside
- ✓ Position the limb in the splint correctly
- ✓ Apply the splint straps
- ✓ Check to ensure splint is fitted well.

4) How to clean the splint

- ✓ Clean the splint with soap and water and scrub it with a small brush.
- ✓ Hand wash the Velcro straps
- ✓ Leave the splint to dry (in the open)

PLEASE REMEMBER TO BRING THE SPLINT WITH YOU TO ALL THERAPY SESSIONS.

If you have any questions or difficulties with your splint, please do not hesitate to call the therapist.

Therapist: _____ Date: _____

Phone#: _____



APPENDIX G: LETTERS



**OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT**

20 September 2011

To Whom It May Concern


I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by:
Ms C Tusiime (Physiotherapy)

Research Project:

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

Registration no:

11/8/17


Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

Private Bag X17, Bellville 7535, South Africa
Tel: +27 21 959-2948/9
Fax: +27 21 959 3170
Website: www.uwc.ac.za

A place of quality,
a place to grow, from hope
to action through knowledge

**MENGO HOSPITAL RESEARCH REVIEW COMMITTEE
P.O.BOX 7161
KAMPALA**

1st February, 2012,

Tusiime Christine
Principal investigator
University of the Western Cape

Dear Madam,

**RE: YOUR APPLICATION FOR INITIAL REVIEW OF YOUR RESEARCH
PROPOSAL NO: (216/11-11)**

RE: APPROVAL OF YOUR RESEARCH PROPOSAL NO: (216/11-11).

**TITLE: EXPERIENCES OF CAREGIVERS OF CHILDREN WITH SPASTIC
CEREBRAL PALSY REGARDING SPLINTING IN UGANDA.
(216/11-11)**

I am glad to inform you that the above named protocol of version 216/11-11 was reviewed by the chairperson of Mengo Hospital Research Review Committee who found it to be satisfactory. Approval is hereby granted to you to conduct this study for a period of one year. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to the MHRRC Office.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the MHRRC, and any changes to the research protocol should not be implemented without MHRRC's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

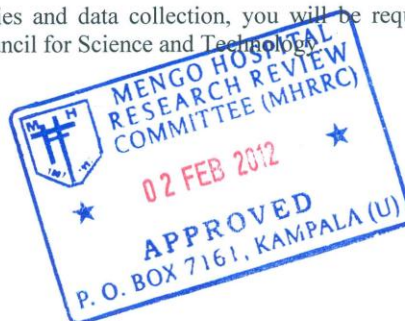
You are reminded to provide this committee with timely progress reports and final report on completion of the research project.

Before commencing with study activities and data collection, you will be required to register it with the Uganda National Council for Science and Technology.

Yours Sincerely,

for Dr. Dambuluma Edith

Prof. M. Kawooya
Chairman (MHRRC)



DEPARTMENT OF PHYSIOTHERAPY

Private Bag X17, Belville, 7535
South Africa
Tel: +27 (0) 21 959 2542/ 2546
Fax: +27 (0) 21 959 1217
E-mail: jfrantz@uwc.ac.za
Website: www.uwc.ac.za

22nd September, 2011

Mrs Connie. K. Tinka,
The Executive Director,
Katalemwa Cheshire Home,
P.O Box 16548
Kampala, Uganda.

Dear Madam,

Re: PERMISSION FOR RESEARCH ON SPLINTING IN CEREBRAL PALSY BY CHRISTINE
TUSIIME

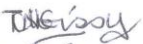
I am a post-graduate student in the Physiotherapy Department at the University of the Western Cape, South Africa. For my degree for the MSc Physiotherapy I need to complete a research project.

My research proposal has been approved by the Senate Research Committee of University of the Western Cape. The research is entitled: Experiences of caregivers of children with spastic cerebral palsy regarding splinting in Uganda.

This is to request for your permission to enable me to conduct data collection for the study at the Cerebral Palsy Clinic at your Physiotherapy Department.

Thank you in advance for your assistance and cooperation.

Yours sincerely,


Christine Tusiime

UNIVERSITY OF THE WESTERN CAPE



DEPARTMENT OF PHYSIOTHERAPY



UNIVERSITY of the
WESTERN CAPE

A place of quality, a place to grow, from hope to action through knowledge

Off: +256 414 590 739
Mob: +256 772 429 427
+256 772 411 908
Fax: +256 414 567 410
P. O. Box 16548,
Kampala - Uganda
8 Km - Gayaza Road
E-mail: katalemwa@infocom.co.ug / kch_director_1971@yahoo.co.uk



Katalemwa Cheshire Home

for rehabilitation Services
www.katalemwacheshirehome.org
katalemwa@infocom.co.ug

10th October, 2011

Ms. Tusiime Christine
University of Western Cape,
Department of Physiotherapy

Dear Madam,

Re: Acceptance of your application to conduct a research project on splinting in Cerebral Palsy

Greetings from Katalemwa Cheshire Home for rehabilitation services

Following your application letter dated 22nd September, 2011 to conduct a research project entitled "experiences of caregivers of children with spastic cerebral palsy regarding splinting in Uganda", I would like to inform you on behalf of management of Katalemwa Cheshire Home that your request has been accepted.

During your research, you will be assisted by Olive Nabiryo, Occupational Therapist, together with the entire team. At the end of this research, you will be required to avail us with a copy of your desertation.

I wish you all the best in your research

Sincerely


Lubega Herbert
Ag. Executive Director



Chairman: Mr John Mary Mpagi, Board Members, Mr. Herbert Muhumuza, Mr. Michael Kaddu, Dr Mukasa Francis, Mrs Joan Mahalanobis, Dr. Deborah Mulumba, Mrs. Miriam Shearman, Mr. Simon Batte, Secretary: Costance Kekihembo



A Member of LCD Global Alliance

DEPARTMENT OF PHYSIOTHERAPY

Private Bag X17, Belville, 7535
South Africa
Tel: +27 (0) 21 959 2542/ 2546
Fax: +27 (0) 21 959 1217
E-mail: jfrantz@uwc.ac.za
Website: www.uwc.ac.za

22nd September, 2011

Mr Simon Bridger,
The Chief Executive Officer,
CoRSU REHABILITATION HOSPITAL
P.O. Box 46
Kampala, Uganda.

Dear Sir,

Re: PERMISSION FOR RESEARCH ON SPLINTING IN CEREBRAL PALSY BY CHRISTINE
TUSIIME


I am a post-graduate student in the Physiotherapy Department at the University of the Western Cape, South Africa. For my degree for the MSc Physiotherapy I need to complete a research project.

My research proposal has been approved by the Senate Research Committee of University of the Western Cape. The research is entitled: Experiences of caregivers of children with spastic cerebral palsy regarding splinting in Uganda.

This is to request for your permission to enable me to conduct data collection for the study at the Cerebral Palsy Clinic at your Physiotherapy Department.

Thank you in advance for your assistance and cooperation.

Yours sincerely,


Christine Tusiime

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21st May 2012

Ms. Christine Tusiime
University of Western Cape,
Department of Physiotherapy

Dear Madam,

Re: Acceptance of your application to conduct a research project on splinting in Cerebral Palsy

In reference to your application letter dated 22nd September, 2011 to conduct a research project entitled **"Experiences of caregivers of children with spastic Cerebral Palsy regarding splinting in Uganda"**, I would like to inform you on behalf of management of CoRSU that your request has been accepted

During your research, you will be assisted by the entire team in the Physiotherapy department of the Hospital. At the end of this research, you will be required to avail us with a copy of your dissertation

I wish you all the best in your research

Sincerely,


Simon Bridger
C.E.O CoRSU



APPENDIX H: TRANSLATED FORMS INFORMATION SHEET

Olupapula oluliko okunyonyola okusingawo

Omutwe: Abazadde abalabirira abaana byebayitamu nga bambaza abaana bano obibayamba okugolola emikono oba amagulu gabwe

Okunonyereza kuno, kuli kuki?

Okunonyereza kuno kukolebwa Christine Tusiime omuyizi mu ssetendekero lye Western Cape mu South Africa. Tukwaniriza wetabe mu kunonyereza kuno kubanga oli muzadde oba olini omwana aliko obulemu obuva ku bwongo nabumuletera okukanyala oba okwefunya mu magulu/emikono nga yafuna ebya mbalwa ebimuyambako mu 2010. Ekigendererwa kyokunonyereza kuno, kwe kutegeza bajjanjabi ba baana abalina obulemu bunno ku bintu ebyenjwulo ababalabirira bye bayitamu nga babambaza ebyo ebibayamba okugolola emikono oba magulu, okusobola okuyimusa omutindo gw'obujjanjabi.

Ki kyenina okola bwemba nsabiddwa okwetaba mu musomo?

Oja kusabibwa okwetaba mukunonyereza nga obuzibwa ebibuzo mu ddwaliro lya CoRSU oba mu maka g'abaana abaliko obulemu e Katalemwa. Ebinayogerwako bijja kukwatta ku magezi n'obumayirivu bw'olina kubikwata n'ebyo abaana abalina obulemu bye bambala okugolola magalu oba emikono gya bwe. Ebibuzo ebinakubuzibwa bijja kumala eddakika 60-90.

Okwetaba kwange mu kunonyereza kuno kunaaba kwa kyama?

Tujja kukola ekisoboka okuuma by'otubulira nga bya kyama. 1) okuma ebyama byo, empapula kwetunawandiika by'onotubulira bijja kutekebwa mu kabadda eriko kufulu era oyo anonyereza yekka nga yagitukako. 2) Tujja kulamba ebyo, byonotubulira, okulamba kuno kwe tunakozesa nga tugabana ebivudde mu kunonyereza. 3) Bwe tuwandiika lipota ku kunonyereza kuno, ebikukwatako bijja kumibwa butiribiri nga bwe kisoboka. 4) Nga amateeka bwegalagira oba enkola y'emirimu jaffe bwelagira tujja kubulira abobuyinza oba bekikwatako ebinatubulirwa mukunonyereza kuno nga birinyirira eddembe lyo oba erya baana, okulagajarira abaana n'okubalumya mubugenderevu.

Okunonyereza kuno, kujjatwaliramu okukwata amaloboozi ku ntambi. Entambi zinno zijja kuyamba anonyereza okufuna ebinava mu bibuuzo. Anonyereza, omuvunuzi, noyo omuwandiisi bokka bebajja okutuuka ku ntambi zino era kabadda ezinatereka entambi zino zijja kusibibwa nga akulira okunonyereza yekka yazitukako. Entambi zijja kusanyizibwawo nga wayisewo emyezi Mukaga okunonyereza nga kuwedde.

- Nzikiriza okwata eddoboozi lyante kulutambi bwenaba nenyigira mu kunonyereza kuno
- Sikiriza kutwala ddoboozi lyange kulutambi nga nenyigira mu kunonyereza kuno

Kabi ki akayinza okuva mu kunonyereza kuno?

Tewali kabi kona kamanyiddwa kayinza kuva mu kunonyereza kuno.

Migaso ki egiyinza okuva mu kunonyereza kuno?

Okunonyereza kuno tekuliwo kuganyula muntu ssekinomu nga gwe, naye ebinavamu bijja kuyamba anonyereza okweyongera okukuguka mu nsonga ezikwata ku byambazibwa abaana abaliko obulemu okusobola okugolola magulu oba emikono gyabwe. Tusuubira nti mu maso, okunonyereza kuno kujja kuyamba abantu abalala abalina abaana abaliko obulemu. Ebinava mu kunonyereza bijja ku kozesebwa okuwa amagezi oba okuwabula mu ngeri y'okukozesa ebyambazibwa mu magulu oba emikono gy'abaana ngabali ewaka. Era ebinava mu kunonyereza bijja kuyamba abajanjabu okutegeza bazadde bye betaaga okumanya okusobola okwambaza abaana bano ebyo ebigolola emikono n'amagulu gabwe nga bali ewaka. Kino kijja kukendeza ku bulumi abaana bwe bafuna nga obulemu bw'okugongobala oba okwefunya ebiva mu butakozesa ebigolola amagulu/emikono. Bwetukendeza okugongobala oba okwefunya, kijja ku kendeza ku bisale oba sente ezisasanyizibwa mu kujanjabu abaana abalina obulemu bw'okukakanyala oba obutefunya.

Okwetaba mu kunonyereza kuno kwa kyeyagalire. Osobola okusalawo obutakwetabamu. Bwosalawo okwetaba mu kunonyereza kuno, osobola okuvamu essawa yona. Bwosalawo obutakwetabamu, oba bwolekerawo okwetabamu, tetujja ku kuvunana era tekijja kukosa kujanjabu kw'omwano wo.

Bwemba nina ebibuza?

Okunonyereza kuno, kuleteddwa Christine Tusiime omuyizi mu ssetendekero lya Western Cape. Bwoba olina ebibuuzo ku kunonyereza kuno, mutukirire kundagiriro eno:

Christine Tusiime

CoRSU, P. O. Box 46, Kisubi, Uganda

Essimu: 0702 266 976

Email: xtinetussy@gmail.com

Bwoba olina ebibuzo ebilala ebikwata ku kunonyereza kuno, oba ku dembe lyo nga eyetabye mu kunonyereza, oba wetaga okwogera ku buzibu bwona bw'ofunye obukwata ku kunonyereza , tukirira;

Prof: Julie Phillips

Dean of the faculty of community and Health Sciences: Prof. Mpofu

University of the western cape

Private Bag X17

Bellville 7535

Okunonyereza kuno okukakasiddwa olukiiko olukulu olwa ssetendekero wa Western Cape.



CONSENT FORM

Olupapula olukiriza:

Erinnya ly’okunonyereza kuno: Abazadde bye bayitamu nga balabirira abaana abaliko obulemu obuva ku bwongo nebuletta okukakanyala oba obuteweta mu mikono/amagulu wano mu Uganda

Okunonyereza kuno, kunyinyonyoddwa mu lulimi lwentegera, era nzikiriza kyeyagalire okukwenyigiramu. Ebibuzo byange ku kunonyera kuno bi diddwamu. Ntegera nti ebinkwatako tebijja kwatulwa mulujudde era ne bwemba nsazewo okuva mukunonyereza kuno, nsobola okuvamu nga siwadde nsonga yonna, nga kino tekinkosa bubi mu ngeri yonna.

Erinnya lyange:

Eky’enkumu:

Abaddewo:

Ennaku z’omwezi:

Bwoba olina ebibuzo byonna ebikwata ku kunonyereza kuno oba wetaaga okutubulira ebizibu byosanze tutukirire kundagiro eno wamanga:

Akulira okunonyereza: Christine Tusiime

Ku ddwaliro lya CoRSU

P.O. Box 46, Kisubi – Uganda

Email: xtinetussy@gmail.com

INTERVIEW GUIDE

Ebibuzo:

Abazadde bye bayitamu nga bayambaza abaana abaliko obulemu obuva ku bwongo ne buletta okukakanyala oba obuteweta mu mikono/amagulu, nga babbambaza ebikozesebwa mu kugolola emikono oba amagulu gano

Okuddako ebamega:

Gw'obuuzza muwe eddembe yetaye: Nnyonyola ekigendererwa ky'ebibuuzo.

- Anonyereza yeyanjula eri omuzadde oba alabirira omwan, anyonyola ensonga era omugaso oguli mu kwetaba mu kunonyeraza era bakakasa nti ebinakuvamu bijja kumibwa mu kyama.

Ekibuuzo:

Mbulira byosanga nga oyambaza omwana ebyo ebimuyamba okugolola magagulu oba emikono

Ebibuuzo ebidako:

1. Omusawo bwe yakugamba okukozesa ebiyamba okugolola amagulu oba emikono, mitenderera ki gyewa yitamu okubifuna?
2. Ani yakusomes okokozesa abyambalwa bino? Era yakusomesa atya?
3. Omwana ye, yanyonyolwa atay? Omwana aberamu mu byogerebwa wakayi wo n'omusawo?
4. Abaana abalala emikwano wamu nebemirirwano bayogera ki kwebyo omwana byalina okwambala?
5. Obugatto buno oba ebyambalwa bitera okuddugala oba okumenyeka?
6. Omwana bwagenda akula kiki ekiberawo?
7. Sente meka ezikozesebwa mu kozesa ebyambalwa bino? Era sente meka ezokugenda mu dwaliro?
8. Omalako otya nábaana abalala ngógenze muddwaliro?
9. Biki omwana byasobola okola nga ali ewaka? Waliwo omwana byatasobola kola nga ali waka?

10. Akagato oba ebyo omwana byayambala, byaletawo enjawulo mu bulamu bwe obwabulijjo? Kati omwana asobola okuzanya ennyo oba nedda? Asobola okweyambaza bulungi oba nedda?
11. Ate okunaaba mungalo ngaagenda okulya oba bga ava mukabuyonjo?
12. Osobola okumpa eby'okulabirako ebirungi oba ebibi byosanga nga oyambaza omwana ebimuyamba okugolola amagulu oba emikono
13. Olowooza ki, ku bintu by'omwana byalina okwamba okugolola amagulu oba emikono era lwaki?
14. Nzikiriza ki zolina kwebyo omwana byalina okwambala okugolola amagulu oba emikono?
15. Nyinyola engeri jobimwambazamu
16. Obugato oba ebyambalwa obimwabaza buli lunaku? Oba bulijjo?
17. Banga ki lyomaze nga oyambaza omwana ebintu bino?
18. Guno gwe mulundi gwo ogusoka okozesa abyyambalibwa bino?
19. Bizibu ki by'osanga mukozesa ebigolola magulu oba emikono gy'omwana?
20. Ovunuka otya ebizibu bino?
21. Osuubira ki mukozesa ebya mbalibwa okugolola amagulu g'omwana oba emikono era lwaki?
22. Onogenda mumaso nokozesa ebyambala bino?
23. Olinayo ekirala ekikwata ku byambalibwa omwana okugolola amagulu oba emikono jje byoyagala twogereko?

Webale nnyo!!!