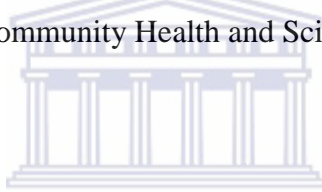


**EXPERIENCES OF CAREGIVERS OF CHILDREN WITH SPASTIC CEREBRAL
PALSY REGARDING SPLINTING IN UGANDA**

BY

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KEYWORDS

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Orthotics / Splints

Physiotherapy

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ABBREVIATIONS

CP	Cerebral Palsy
ICF	International Classification of Functioning, Disability and Health
WHO	World Health Organisation
KAFO	Knee-ankle-foot orthosis
AFO	Ankle-foot orthosis
<i>n</i>	Number
USA	United States of America



DEFINITION OF TERMS

- Caregiver:** Anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help, for example a child with CP (Family Caregiver Alliance, 2012).
- Contracture:** Muscles that are too short (Gage et al., 2004).
- Deformity:** Mal-alignment of bone caused by muscle shortening resulting in distortion of a joint (Driscoll & Skinner, 2008).
- Dynamic (functional) splint:** Splint used to improve function of a limb (Rosen, McColey & Bowker, 1987).
- Lower limb splint:** Splint for the leg can extend from hip to ankle, including foot.
- Resting (rigid) splint:** Splint used to maintain functional position of a limb (Rosen, McColey & Bowker, 1987).
- Spasticity:** Motor disorder characterized by a velocity-dependent increase in tonic stretch reflexes (muscle tone) with exaggerated tendon jerks (Lance, 1980).
- Splint / Orthosis:** Rigid or flexible device intended to enhance function, protect the limb in a functional position and to prevent contractures (Lehneis, 1977).
- Upper limb splint:** Splint for the arm, includes wrist, hand and fingers.

ABSTRACT

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

Splinting is one of the many strategies used globally for managing neuromuscular impairments related to cerebral palsy. In Uganda, some children with cerebral palsy who have been provided with splints return to the physiotherapy department with contractures or deformities. A qualitative research methodological approach was used to understand and describe the experiences of caregivers of children with cerebral palsy regarding splinting in Uganda. The theoretical framework used was the bio-psychosocial model of disability. Purposive sampling was used to select 24 caregivers of children with spastic cerebral palsy who received splints in 2010 at two research settings in Uganda. In-depth interviews were conducted with all the participants at their homes using an interview guide. The data collected was transcribed verbatim and translated from Luganda to English. Inductive content analysis was used to analyse the data. Six themes concerning experiences emerged, namely: caregivers' expectations and beliefs; acquisition of splints; knowledge and skills; attitudes to splinting; compliance and benefits of splinting. The results of this study show the overwhelming challenges caregivers face while their children require splinting. When considering providing splints to children, the results highlight the need, to take into account the personal (child) factors, the splint characteristics and the environmental (family and community) factors. There is a need to provide information on splints to both the children with cerebral palsy and their caregivers.

May 2013

DECLARATION

I declare that *Experiences of caregivers of children with spastic cerebral palsy regarding splinting in Uganda* is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Signed: _____

Christine Tusiime



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Dedication

I dedicate this thesis with love and appreciation to my first role model: my mother, Winifred Kobujuna, who taught me by a wonderful example how to love and to care for a child with disability; my sister, Maureen Kemigisha. Thank you for all that you have done to help me to become the person I am today. May God continue to bless and reward you abundantly.



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CHAPTER 1: INTRODUCTION

1.1 Introduction

In this chapter the background to the study is described and the research problem is stated. The research question is then formulated and the aim and objectives for this study stated. This is followed by a brief description of the theoretical framework. The motivation for the study is also explained.

1.2 Background of the study

Globally it is estimated that between 120 and 150 million children below 18 years have disabilities (UNESCO, 2012). The International Classification of Functioning, Disability and Health (ICF) defines disability as an umbrella term encompassing the outcome of the interaction between a person's impairments, activity limitations or participation restrictions and environmental factors that affect these domains (WHO, 2001). There are at least 81,200,000 people affected by some form of disability in Africa, and the most common disabilities in are: physical, sensory (visual and hearing), speech impairments and intellectual disabilities (WHO, 2012). The global prevalence of CP is estimated at 2-3 per 1000 live births (Kriger, 2006; Flett, 2003).

According to the Uganda Bureau of Statistics (UBOS, 2002), 4% (976,000 people) of the total Ugandan population of 24.4 million people has a disability with an estimated 30% of people with disabilities being children. But, the Uganda Society for disabled children (2011) estimates that there are over 1,000,000 children with disabilities in Uganda, and that the most common disabilities are epilepsy, mental retardation and CP. Thus, there is no clear statistics in Uganda of how many people have a disability or the prevalence or the incidence of CP.

CP is a movement disorder caused by damage to a developing brain and affects children differently causing mild, moderate, or severe motor problems (Peacock, 2000). CP has a number of problems associated with it such as epilepsy, intellectual disability, learning difficulties, behavioural challenges, sensory (visual and hearing) impairments, speech and language impairments and feeding difficulties (Olney & Wright, 2006). The classification of CP depends on the motor abnormality caused by brain damage (Olney & Wright, 2006). The characteristics associated with the motor abnormality include spasticity, ataxia, athetosis, chorea, dyskinesia, dystonia or rigidity (Bjorklund, 2006).

The spastic type of CP is the most common and potentially most disabling type of CP especially if the distribution involves all limbs (Yeargin-Allsopp, Doernberg, Benedict, Kirby, & Durkin, 2008; Sankar & Mundkur, 2005). Additionally, spasticity is a major cause of contractures in children with CP (Farmer & James, 2001). These contractures are caused by shortening of tissues in and around a joint resulting in the restriction of function (Postans et al., 2010).

Globally, splinting or the use of orthotics is one of the strategies for managing spasticity. Other strategies are oral muscle relaxants, botulinum toxin injections, occupational therapy, physiotherapy, hippotherapy, selective dorsal rhizotomy and intrathecal baclofen (Sharan, 2005). Studies show that there is evidence indicating that sustained stretching using splinting can improve range of movements and also reduce spasticity of targeted muscles of children with spasticity in CP (Pin, Dyke & Chan, 2006; Flett, 2003). Postans et al. (2010) also suggest that by stretching the spastic muscles, splinting in CP can be used as a long-term measure to prevent contractures from forming or recurring. According to Russo, Atkins, Haan & Crotty (2009) children with CP have significant physical limitations that may require the use of splints. Some children may require splints to prevent contractures and deformities or to reduce spasticity or they may be used to facilitate function (Postans et al., 2010; Lundequam & Willis, 2009; Pin, Dyke & Chan, 2006; Flett, 2003). Flett (2003) states that, when children develop contractures and deformities, surgery may have to be performed to restore structure and to correct deformities. This is an extra burden on the child and the family resources (Boyd, Morris & Graham, 2001). Therefore, adherence to splinting is important for successful clinical outcomes (Sandford, Barlow & Lewis, 2008). Thus, according to Singhi (2004) giving caregivers knowledge and skills on how to manage the child at home, by instructing caregivers on home exercise programmes and encouraging usage of splints is important.

1.2.1 Context

This research was done in Wakiso district in the southern part of the central region of Uganda (Ministry of Water and Environment, 2010). According to the Ministry of Water and Environment (2010) Wakiso district has a population of 1,200,900 persons from different ethnic groups with different languages. Wakiso district has two counties and one municipal county with 16 sub-counties and four town councils.

Uganda and its people

Uganda (Map 1) lies across the equator, about 800 kilometres inland from Indian Ocean in East Africa with a total population of 24.4 million, 56% of these are less than 17 years of age (Uganda Bureau of Statistics, 2002). Uganda is bordered by Kenya (East), Sudan (North), Democratic Republic of Congo (West), Tanzania (South) and Rwanda (South West) and has an area of 241,038 square kilometres. According to the Uganda Bureau of Statistics (2002) there are nine ethnic groups each with a population of over one million persons. The Baganda are the largest ethnic group (17%) followed by Banyankore (9.8%), Basoga (8.6%), Bakiga (7.0%), Itesot (6.6%), Langi (6.2%), Acholi (4.8%), Bagisu (4.7%) and the Lugbara (4.3%). These ethnic groups all speak different languages. According to the Uganda Bureau of Statistics 68% of the population aged 10 years and above are literate (can write or read with understanding in one language), 42% of all persons aged 10 years and above are self-employed, 15% are employed persons, 39% are unpaid family workers and 4% of the total labour force are unemployed. Of the working population 71% are engaged in subsistence agriculture, 7% are professionals, semi-professionals and administrators while 9% are sales and service workers.



Map 1 Accessed on 4/07/2012, time: 20:29 from <http://www.worldatlas.com/webimage/countrys/africa/lgcolor/ugcolor.gif>

In Uganda, disability is defined as permanent and substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation (Government of Uganda, 2003).

1.2.2 Splinting process

In Uganda in order to acquire a splint, the child with CP has to be assessed at the health clinic by a physiotherapist, occupational therapist or orthopaedic surgeon. Once the assessment is done, the child is then referred to the orthopaedic workshop where the measurement for the splint is done. The orthopaedic technician manufactures the splint. Close communication is necessary between technician and the therapist. Splints are custom-made from a plaster model of the child's extremity and fabricated using plastic material. There is usually a waiting time before the child can be fitted with the splint. Once the child is fitted with the splint, the child then takes the splint home and is expected to use it at home as part of home therapy.

PERSONAL REFLECTION

I have worked as a registered physiotherapist in Uganda for the last nine years. I worked at a rehabilitation centre for children with disabilities for the first six years after qualification prior to joining a rehabilitation hospital for people with disabilities for the last three years. During this time I have seen splints improve the function of some children, prevent deformities in some children and relax the muscles of some of the children. I have also seen some children return after months or years of "using the splints" with contractures or deformities. The children do not stay at the rehabilitation centres during the splinting process. Once the children obtain the splints they go home and are expected to use the splints daily. Caregivers are given verbal instructions on how to manage with the splint at home but there is no documentation given to them.

At times, children with CP have to depend on caregivers to assist them with the use of the splint. I have wondered if the reasons for the contractures are in any way linked to the caregivers' application of the splints. I have often wondered if children with CP, who have been issued splints, would not return to the physiotherapy department with contractures or deformities, if the splints had been used as prescribed. However, there is no documentation regarding caregivers' experiences during splinting to understand what happens at home and if the splints are being used as prescribed. Therefore I hope this research will help to capture

some of the information required to make recommendations on how to improve the experience of splinting for the caregivers of children with spastic CP.

1.3 Statement of the problem

In Uganda some children with CP are provided with splints to prevent contractures and deformities, reduce spasticity, and facilitate function. However, while working with these children, the researcher observed that some children who have been issued with splints return to the physiotherapy department with contractures or deformities. As a result they need surgery or serial casting and splinting to correct the contracture or deformity which is costly for the family and causes the child pain that could have been prevented. It is not known why this has happened and many therapists assume it is because splints are not used at home as prescribed.

1.4 Theoretical framework

The theoretical framework used to understand this study was the bio-psychosocial model of disability and the International Classification of Functioning, Disability and Health (ICF). According to Simeonsson et al. (2003) the ICF is a universal language and standard used to classify components of functioning and disability. Rosenbaum and Stewart (2004) state that the ICF is a universal classification system focusing on the components of health, within which disability is viewed as a social construction involving interaction of a person and their community. These authors further state that the ICF enables therapists to talk with parents and children about goals for activities and participation in home and society. This is because in using the ICF, the environment in which the person lives is important and needs to be considered during planning treatment or management. Beckung and Hagberg (2002) state that the ICF includes identifying both biological and social factors to determine the impact of health conditions on an individual's life, as well as their participation in society. These same authors further state that the ICF views disability as a consequence of the interaction between biological, personal and social factors of an individual. In the UK, in a study to determine whether the degree of participation of children with CP is influenced by where they live, Hammal, Jarvis and Colver (2004) suggest that the environmental factors play an important role in determining what the child does. In this study, the domain of social exclusion seemed to be explained entirely by where the children lived and not by other factors such as the type of CP, degree of intellectual impairment or even restricted walking ability. However, these authors had some reservations about the instrument used to measure participation as it did not

cover all relevant domains such as behavioural exclusion. They also had reservations since they may not have represented intrinsic differences between children regarding case-mix and personal factors since they had no data on personal coping styles and aspirations.

The ICF was used in this study to understand the social factors 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 ICF (WHO, 2001) uses the term contextual factors to describe environmental and personal factors that affect the health of an individual with a health condition.

1.5 Motivation for the study

In a study by Kuipers et al., (2009, p. 368) they opine that:

“In order to promote regular use of splints by clients with upper limb spasticity, therapists need to understand the reasons behind use and non-use of splints by clients. This might help to provide more reliable results from splint wearing and better therapeutic outcomes in the long term.”

Similarly, Huang, Sugden and Beveridge (2008) state that providing assistive devices to children is only the beginning, research about use of the devices is essential in order to maximise the benefits of the devices. Since children with CP usually have impairments that require them depend on caregivers' assistance to use the splint it is important to explore the caregivers' experiences of splinting in order to try to understand why the children are developing contractures. Currently in Uganda, there is no information on why children who are provided with splints are still getting contractures and deformities. This makes it difficult for health professionals involved in the splinting process to know what they can do to further support caregivers' role in the splinting process.

1.6 Research question

This study planned to answer the question: “What are the experiences of caregivers of children with spastic CP regarding the splinting process in Uganda?”

1.7 Aim

The aim of this study was to describe the caregivers' experiences regarding splinting.

1.8 Objectives of the study

The objectives of this study were:

1. To explore caregivers' positive and negative experiences of splinting their children
2. To explore caregivers' views and opinions about splinting their children
3. To describe the caregivers' experiences of applying splints to their children
4. To describe the caregivers' expectations from splinting their children

Summary

CP is a motor disorder caused by damage to a developing brain. The characteristics associated with this motor disorder include spasticity, ataxia, athetosis, chorea, dyskinesia, dystonia or rigidity. 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 is not known why this has happened and many therapists assume it is because splints are not used at home as prescribed. From the researcher's experience, prescribing splints to children to prevent contractures and deformities is not enough, because therapists tend to rely on the caregivers of children with CP to carry on with the splinting as part of the home therapy program. Hence, there is 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. A presentation of the relevant literature reviewed follows in the next chapter.

1.9 Outline of other chapters

This thesis consists of five more chapters which follow Chapter One. Chapter Two presents the literature review in relation to the research topic. The chapter starts with literature about the definition of CP, prevalence and causes of CP, types of CP, as well as problems associated with CP. This is then followed by a review of the multidisciplinary management of CP, with emphasis on the role of family and physiotherapy. Spasticity a major complication of CP is then reviewed. Literature about management of spasticity is then presented. The chapter ends with the factors that influence adherence to splinting as identified in available literature.

Chapter Three presents the methodology used in this study. First, the two study settings are presented. Secondly, the study design, population, and the sampling method used are described. Thirdly, the procedures used in data collection are presented. Furthermore, the instrument used to collect data is then described. Lastly, the methods used to analyse data are described, as well as the ethical procedures followed before and during the study.

Chapter Four presents the results for the study. The chapter begins with presenting the demographic characteristics of the participants. A summary of the six themes that emerged is then presented. This is followed by presentation of each theme in detail. The themes that emerged are caregiver's expectations and beliefs, acquisition of splints, knowledge and skills, attitudes to splinting, compliance, as well as benefits of splinting.

Chapter Five begins with a discussion of the caregivers' expectations and beliefs about splinting. This is followed by discussing what transpires during acquisition of splints. The caregivers' knowledge and skills regarding splinting is then discussed. A discussion about the attitudes from the child, caregiver and community regarding splinting then follows. The challenges caregivers experience during splinting that affect compliance in relation to those identified in literature are then discussed. Lastly, the benefits of splinting as stated by the caregivers are discussed.

Chapter Six, the final chapter summarises the whole study. This chapter includes the limitations of the study, recommendations for changes that can be made to improve the splinting process, as well as recommendations for future research.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

A literature search of the following databases was undertaken: EbscoHost, Cambridge Journals Online, CINAHL, Google Scholar, Medline, Rehabilitation and Sports Medicine Source, SAGE Journals Online, Science Direct, Health Source: Nursing / Academic Edition, BioMed Central, Springer Link and Wiley Online Library. The key words used during the search included: CP; spasticity; splinting; caregivers; experiences; braces; assistive devices; orthotics; orthoses and splints. Different combinations of the key words were also used. Reference lists of some of the articles in the search results were also used to obtain other articles that were not available in the search results. This is a narrative review of literature obtained from the various databases and not a systematic review. This literature review looks critically around issues regarding caregivers of children with CP and splinting. Firstly, the definition, prevalence, causes, types of and problems associated with CP are outlined. This is then followed by a description of the role of different medical professions in the management of children with CP. Spasticity as a key characteristic in CP is also reviewed. The review discusses the literature on splinting as a management technique for spasticity in CP. This includes: evidence for splinting; types of splints used in CP and the personnel involved in splinting. As caregivers play a major role in determining whether children with CP use the splint or not while at home, factors pertaining to splinting and caregivers are reviewed. This includes the role of the caregivers in splinting, experiences of caregivers during splinting and the factors influencing adherence to splinting instructions.

2.2 Definition of CP

It has always been a challenge to define CP as noted by the different definitions that several authors have come up with. The executive committee for the definition of CP, Bax et al. (2005, p. 572) proposed that:

“CP describes a group of disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder.”

Parkes and Hill (2010) state that CP refers to a group of motor impairments that affect voluntary movement and posture, that have different causes, clinical presentations and implications for the child and family. Peacock (2000) states that CP is a movement disorder caused by damage to a developing brain and affects children differently causing mild, moderate, or severe motor problems. Law et al (2007) define CP as a group of non-progressive movement disorders as a result of brain damage that may occur prenatally, perinatally or in early childhood. According to Kibel and Wagstaff (1995), although the brain lesion is non-progressive, the clinical manifestations often change with neurological maturation. Balf and Ingram (1955, p. 163) defined CP as “a group of motor disorders of young children, in whom full function of one or more limbs is prevented by paresis, involuntary movement, or incoordination.” There is not a single universally accepted definition of CP. However, there is common agreement that voluntary movement and posture are affected as a result of damage to the developing brain. Although non-progressive the clinical manifestation may change. .

There has been progress in classifying children’s movement and manual abilities since these are easier to observe. Kerr, McDowell and McDonough (2006) state that the severity of disability caused by CP ranges from mild to severe depending on the specific location of brain damage. Clues to diagnosis of CP include observation of slow motor development, abnormal muscle tone and unusual posture (Kriger, 2006).

2.3 Prevalence of CP

The global prevalence of CP is estimated at 2-3 per 1000 live births (Kriger, 2006; Flett, 2003). The prevalence of CP in developed countries is estimated at 2 per 1000 children (Winter, Auntry, Boyle, and Yeargin-Allsopp, 2002; Finnie, 1997). During the period from 1975 to 1991 developed countries reflected an increase in the overall prevalence of CP from 1.7 to 2.0 per 1000 as a result of increase in survival of babies with congenital heart diseases, pre-term and low-birth weight deliveries (Winter et al, 2002). This was attributed to the use of advanced medicine and technology. Flett (2003) estimated the CP prevalence in Australia to be 2.0 - 2.5 per 1000 live births.

It is estimated that 85% of children with disabilities under 15 years of age live in developing countries (Helander as cited by Shawky, Abalkhail & Soliman, 2002). According to the Uganda Population and Housing Census Report (UBOS, 2002) the disabilities in Uganda include: loss or limited use of limbs (35.3%), serious spine problems (22.3%), hearing

impairments (15.1%), visual impairments (6.7%), mental illness (3.6%), mental retardation (3.6%), speech (3.9%) and other disabilities (9.6%). Disability prevalence increased with age from 2% among children aged less than 18 years to 18% among elderly. Furthermore, 13% of people with disabilities have multiple disabilities. The Report also states that 30% of people with disabilities are children. The distribution of children with disabilities shows that the age group 10 -14 years had the highest proportion of children with disabilities, while the 15 -17 years age group had the lowest proportion and that there are no major gender differentials among the different subgroups; 31% had mobility problems, followed by hearing problems (26%) and sight difficulty (15%).

2.4 Causes of CP

Despite CP being the commonest childhood physical disability; in many cases the cause is unknown (Reddihough & Collins, 2003). According to Wu and Colford (2000), the aetiology of brain injury is poorly understood and how the various factors interact to cause neural injury is unknown (Idro et al., 2010). However, factors that may result in CP are classified in three broad groups, namely prenatal, perinatal and postnatal factors (Law et al., 2007; Ashwal et al., 2004; Reddihough & Collins, 2003; Kibel & Wagstaff, 1995). Thus, a child may be born with CP or acquire it after birth (Blair & Watson, 2006).

Prenatal causes include factors that may interfere with the foetal development while in the uterus such as: genetic factors, developmental malformations, intra-uterine infections and pregnancy complications such as eclampsia or multiple pregnancies (Bax, Tydeman & Flodmark, 2006; Reddihough & Collins, 2003; Pharoah & Cooke, 1996). Krigger (2006), states that pre-natal risk factors for CP include intrauterine growth retardation, intracranial haemorrhage and trauma. In a study in Europe, Bax, Tydeman and Flodmark (2006) showed that 29% of mothers of children with CP had infections during pregnancy, and 12% of children with CP were from a multiple pregnancy (twin or triple pregnancy). In the counties of Merseyside and Cheshire in the United Kingdom, using a population based register to compare the prevalence of birth weight specific CP in singleton and multiple births, Pharoah and Cooke (1996, p. 175) observed that: “twins of normal birth weight (≥ 2500 g birth weight) are at a higher risk of CP than singletons, and that in the low birth weight groups there is no significant difference in risk”. This indicates that twins are at a higher risk of CP. These authors also state that there is increased risk of CP if the co-twin died in utero in twin pregnancy. Reddihough and Collins (2003) in Australia identified prenatal causes such as: congenital brain malformations, cerebral artery occlusion, and maternal infections during first

and second trimesters like rubella, cytomegalovirus or toxoplasmosis. Other prenatal causes these authors identified include: metabolic disorders, maternal ingestion of toxins and rare genetic syndromes.

Perinatal causes include complications that could occur before and during the process of delivery. Perinatal causes include: prematurity and associated complications, perinatal asphyxia, birth trauma (obstructed labour, antepartum haemorrhage or cord prolapse), bilirubin, encephalopathy, hypoglycaemia and intracranial haemorrhage (Reddihough and Collins, 2003). Intrapartum hypoxic ischemia usually occurs as a result of interruption of placental blood flow and gas exchange, and is usually referred to as asphyxia (Perlman, 1997). Other peri-natal factors include premature birth of less than 32 weeks of gestation, and low birth weight of less than 2500 grams (Bax, Tyderman, & Flodmark, 2006; Krigger, 2006). However, Stanley and Watson (1992) argue that CP in low birth weight infants is caused by postnatal events and not antenatal events.

The postnatal acquired causes include complications that could occur after the process of delivery. These include some cerebral infections such as: catastrophic infections (cerebral malaria, bacterial meningitis and viral encephalitis), cerebral malaria, trauma and cerebrovascular accidents (Krigger, 2006; Reddihough and Collins, 2003). Additionally, Reddihough and Collins (2003) identify meningitis, septicaemia and injuries which occur after birth as causes of acquired CP.

In Uganda the common causes of CP are postnatal factors, in particular catastrophic infections such as cerebral malaria (Idro et al., 2010), bacterial meningitis, and viral encephalitis (Egdell & Stanfield, 1972). Egdell and Stanfield (1972) also suggest that the effect of these infections is compounded by the delay in their treatment. Idro et al. (2010) has also identified epilepsy as a common cause. In a case-control study in Uganda, Kaye (2003) identified factors that may act in utero to cause birth asphyxia. These included maternal illness, obstetric complications and environmental factors. In this study, maternal illness included malaria and urinary tract infection; obstetric complications included antepartum haemorrhage, preterm rupture of membranes, anaemia and hypertensive diseases in pregnancy, while environmental factors included trauma during labour or malnutrition. According to Idro et al. (2010, p. 104); “CP is the most severe neurological complication of falciparum malaria.”

2.5 Types of CP

CP classification depends on the motor abnormality caused by the brain damage (Olney & Wright, 2006). Balf and Ingram (1955) presented neurological terms to describe manifestations of CP during research on the prevalence and aetiology of CP. These included: hemiplegia, double hemiplegia, diplegia, ataxic diplegia, ataxia and dyskinesia. Currently, classification of CP is dependent on the type of the motor abnormality and the part of the body affected (Bjorklund, 2006; Howard et al., 2005).

According to Bjorklund (2006), the motor abnormality may be: spasticity (person's muscles are stiff and tight); ataxia (person has uncoordinated movements); athetosis (person has slow and twisting movements); chorea (person has sudden jerky movements); dyskinesia (person has uncontrollable involuntary movements); dystonia (person has repeated twisting posture of the body); or rigidity (where there is overly tense muscle tone). According to Krigger (2006), characteristics of athetoid/ dyskinetic type of CP include abnormally slow, writhing movements of the hands, feet, arms and or legs. This author also states that ataxic CP usually causes impairment of balance and co-ordination.

Additionally, the types of CP are clinically characterized by the part of the body affected or the topographical distribution (Rosenbaum, 2003). These include; monoplegia (one limb which may be the arm or the leg is affected), diplegia (arms and legs are affected with legs more affected), hemiplegia (arm and leg on the same side of body are affected), triplegia (three limbs are affected), or quadriplegia where all limbs are affected (Lagunju & Adedokun, 2008; Finnie, 1997). Ostensjo, Carlberg, and Vollestad (2004) in a study to describe the relationships within and between body functions, activities and participation domains of ICF, state that the topographical distribution of involvement in CP is the most predicting factor of gross motor function, mobility and self-care. However, Howard et al. (2005) think the best way to classify children with CP is using a combination of motor type, topography and gross motor function. These authors also recommend using the Gross Motor Function Classification System (GMFCS) as a tool for improvement of communication between health professionals.

In Victoria, Australia, in a study to describe the proportion of each motor type of CP in a population register of children with congenital CP, Reid, Carlin and Reddihough (2011) stated that between 1970 and 2003 the predominant types of CP were spastic (91%), ataxic (5%), and dyskinesic (4%). This is almost similar to a study in Nigeria comparing

quadriplegic and hemiplegic types of CP, where Lagunju and Adedokun (2008) identified four key findings. Firstly, the authors state that spastic quadriplegia is the most severe form of CP, and that children with this type of CP had a higher incidence of intellectual impairment and speech defects. Secondly, according to these authors, children with hemiplegia had a higher incidence of epilepsy. Thirdly, these authors also identified that children with spastic quadriplegia had a lower quality of life and functional independence than those with hemiplegia. Fourthly, they stated that children with spastic quadriplegia required medico-social support which is lacking in developing countries. Likewise, Yeargin-Allsopp et al. (2008) state that the spastic type of CP is the most common, and disabling classification, especially if distribution involves all limbs. Furthermore, Howard et al. (2005) state that children with spastic quadriplegia have the lowest levels of function when compared to children with hemiplegia or diplegia.

Spastic quadriplegia may occur as a result of parasagittal cerebral injury (Perlman, 1997) or damage across all areas of white matter (Bax, Tyderman & Flodmark, 2006). Perlman (1997) states that parasagittal cerebral injury affects the motor cortex that controls proximal extremity function, and results in the upper extremities being more severely affected than the lower extremities. Furthermore, spastic quadriplegia with visual and cognitive impairments may be caused due to periventricular leukomalacia. This type of injury affects white matter adjacent to the external angles of the lateral ventricles, centrum semiovale, optic and acoustic radiations. In this type of injury, moderate lesions may affect the function of the lower extremities only but severe lesions affect the upper extremities as well. In addition, Perlman (1997) states that spastic hemiplegia or quadriplegia with seizures may be a result of focal/multifocal ischemic brain necrosis which causes injury to all cellular elements and is usually due to an infarction within a vascular distribution.

Diplegia is usually caused by white matter damage of immaturity, and this injury is thought to occur before 34 weeks of gestation (Bax, Tyderman & Flodmark, 2006). Spastic diplegia that presents with visual and cognitive impairments may be caused due to periventricular leukomalacia (Perlman, 1997). Bax, Tyderman & Flodmark (2006) state that choreoathetosis is usually as a result of perinatal hypoxic ischemia which causes neuronal injury in the basal ganglia. The basal ganglia include the thalamus, caudate nucleus, globus pallidus and putamen. Dystonic CP is mainly associated with basal ganglia and thalamic damage, while hemiplegia is mainly associated with focal cortical infarcts (Bax, Tyderman & Flodmark, 2006; Mercuri et al., 1999). In addition, spastic hemiplegia associated with seizures may be a

result of focal/ multifocal ischemic brain necrosis which causes injury to all cellular elements and is usually due to an infarction within a vascular distribution (Perlman, 1997).

2.6 Conditions associated with CP

CP always involves a motor deficit and as such the child usually has delayed motor milestones (Langunju & Adedokun, 2008; Ashwal et al., 2004). CP also has a number of other conditions associated with it including learning difficulties, behavioural challenges, sensory (visual and hearing) impairments, speech impairments, feeding difficulties (Malik et al., 2007; Olney & Wright, 2006; Ostensjo, Calberg & Vollestad, 2004), intellectual impairment and epilepsy (Ashwal et al. 2004). These may be caused by hypoxic- ischemic encephalopathy (Perlman, 1997). In Europe in a study to describe psychological symptoms in children with CP aged between eight to 12 years, Parkes et al. (2008) state that a significant proportion of children with CP have psychological symptoms which may necessitate referral to specialist services.

In a study in Europe Bax, Tyderman and Flodmark (2006) found that 28% of children with CP had epilepsy, 58% had communication problems, 7% had a hearing impairment and others had visual impairments. Malik et al. (2007) identified oromotor impairments such as drooling, swallowing difficulty, gastroesophageal reflux and speech impairment as associated problems in children with CP. These authors also identified visual impairments such as strabismus, squints, nystagmus, blindness and optic atrophy. Furthermore, these authors noted that growth failure may occur as a result of feeding problems, gastroesophageal reflux, inability to independently access food and having recurrent infections. In addition, 67% of the children in this study had deformities in the form of contractures and scoliosis, as a result of increased tone which prevented performance of activities. Also, 25% had aspiration pneumonia as a result of swallowing difficulties, 35% had dental caries which they attributed to dental enamel dysplasia and 15% had neuro-behavioural disturbances such as short attention span, impulsivity, and distractibility.

Several authors state that the functional problems associated with CP are greatest in children with spastic quadriplegic CP (Chen et al., 2010; Yeargin-Allsopp et al., 2008; Bax, Tyderman & Flodmark, 2006; Ostensjo, Carlberg, & Vollestad, 2004; Perlman, 1997). Vasconcelos, Moura, Campos, Lindquist and Guerra (2009) noted that children with severe motor impairments have less independence in functional skills and are therefore more dependent on caregivers. Functional impairments associated with CP include reduced function of lower

limbs such as difficulty in walking or crawling (O'Shea, 2002). Other functional impairments highlighted by O'Shea (2002) include reduced function of upper limbs such as difficulty with writing or feeding, as well as functional impairments caused by reduced cranial nerve function such as difficulty with swallowing or eye movements. In a review of studies related to constraints on balance and walking in children with CP, Woollacott and Shumway-Cook (2005) state that poor walking and manipulation skills in CP are caused by poor balance control. This is caused by delayed onset of muscular contractions, activation of proximal muscles before distal muscles and increased co-activation of antagonist muscles with agonists that occurs in children with CP.

2.7 Management of CP

The management of CP requires a multidisciplinary team approach. This section includes a discussion on the multidisciplinary management, the roles of the family and the roles of physiotherapy in the management of a child with CP.

2.7.1 Multidisciplinary management

As stated by Krigger (2006) the management of children with CP is dependent on the child's specific symptoms. This author further states that since children with CP are at high risk of peer rejection and social isolation, care plans for these children should decrease barriers to participation at school and community activities, and be based on the bio-psychosocial model of health care delivery that includes family dynamics and all concerned. The main goal of management of CP is to maximise participation for the child in the society (Sorsdahl, Moe-Nilssen, Rieber & Strand, 2010). Other goals for health care of a child with CP are promoting function, acquisition of new skills, as well as educating caregivers about daily care of the child (Jones, Morgan & Shelton, 2007).

In order to address all the associated problems, CP management requires a multidisciplinary team approach which may include the following professions, depending on the country and context: neuro-developmental paediatrician, physiotherapist, occupational physiotherapist, clinical psychologist, speech and language pathologist, orthopaedic surgeon, otorhinolaryngologist, ophthalmologist, dietician, teacher, play therapist and social worker (Palisano et al., 2009; Patel, 2005; Singhi, 2004). According to Krigger (2006) each of these professions has a role to play in the management of the child with CP.

In a study in the United States of America (USA), Palisano et al. (2009) found that the role of health professionals is to assist the families of children with CP to prepare for key periods in

the child's life. The neuro-developmental paediatrician synthesizes long-term comprehensive plans including medical treatments for the child (Kriger, 2006). Flett, Connell, Seeger & Gibson (2009) noted that pharmacological agents such as baclofen, diazepam, and dantrolene can be used to reduce spasticity. These authors, also state that botulinum toxin A is of similar efficacy as serial fixed plaster casting, in improving dynamic calf tightness in ambulant, or partially ambulant children with CP. In a study to document effects of botulinum toxin A injections into the gastrocnemius muscles in children with spastic diplegia, Bjornson et al. (2007) state that physiologic and mechanical effects of botulinum toxin A are measurable and genuine, but may not create enough change in the patient's function or the families' perception of function in order to register a meaningful improvement in societal participation. According to Flett et al. (2009) selective dorsal root rhizotomy performed by a neurosurgeon, seems to be effective in reducing spasticity. However, this is only effective when performed in a carefully selected group of patients.

The roles of the physiotherapist are described in detail in Section 2.7.3.

The occupational therapist develops and implements plans focused on daily living activities (Steultjens et al., 2004). For example Louwers, Meester-Delver, Folmer, Nollet and Beelen (2011), state that for children with hemiplegia the role of the occupational therapist is to improve the child's performance in tasks that require bilateral manipulation. In a study to investigate the functional outcomes of botulinum toxin type A injections in combination with occupational therapy in the upper limb of children with CP, Wallen, O'Flaherty and Waugh (2007) state that occupational therapy enhanced functional outcomes.

The speech and language pathologist manages the speech and language impairments of the child. In a study to investigate factors associated with motor speech control in children with CP in Taiwan, Chen et al. (2010), state that therapy for speech impairments should be based on assessment of speech, language and communication, and that treatment should focus on integration of all aspects of voluntary speech control. These aspects include global motor control, focal oro-motor control and sequencing.

The social worker supports the child and family by identifying community assistance programmes (Kriger, 2006). Kriger (2006), states that the psychologist assists the child and family to cope with the stress and demands of the disability. This same author states that the teacher addresses cognitive and/or learning difficulties of the child. According to Hartley and Thomas (2003) the dietician is necessary since weight and length measurements are not

necessarily accurate for determining nutritional status of the child. The dietician is able to perform a variety of anthropometric measurements to improve the assessment of the child's nutritional status.

Appropriately selected and timed releases of tight muscles using orthopaedic surgical techniques are sometimes considered important in the management of spasticity in CP (Flett et al., 2009). Krigger (2006), states that in the management of CP the orthopaedic surgeon focuses on preventing or correcting contractures, dislocations and deformities. According to Graham and Selber (2003) the orthopaedic surgeon is vital for management of common deformities which affect upper and lower limbs, for example an equinus contracture and drop foot can be managed by lengthening the gastro soleus and provision of an ankle-foot orthosis. These authors also state that an equinovarus deformity can be managed by tendon-lengthening and tendon transfers. In a study by House, Gwathmey and Fidler (1981), orthopaedic surgical procedures such as contracture releases and balancing muscle forces improved function in fifty-six patients. Common orthopaedic surgical measures in children with CP include wrist fusion, tenotomy, myotomy, tenodesis, capsulotomy, excision arthroplasty and tendon transfers in the upper limb (Tawde, Athani & Rege, 2002). In the lower limb common orthopaedic surgical procedures include: fusion of metatarso-phalangeal joint of great toe and interphalangeal joints of second and third toes, plantar fasciotomy, talocalcaneal strut fusion, triple arthrodesis, hamstring transfer, adductor tenotomy and varus osteotomy in the lower limbs (Pollock, 1962). Tawde, Athani & Rege (2002) state that surgical interventions in the spastic hand need to be followed with proper post-surgical therapeutic regime which includes hand splints and activity training in order to achieve improvement in hand function.

However, evidence is still lacking for the effectiveness of most professions involved in the management of CP. For example, according to Steultjens et al., (2004) the efficacy of occupational therapy is still inconclusive. As stated in a review article by Dodd, Taylor and Damiano (2002) there is need for health care providers to show that their treatments are effective from the clients' perspective by incorporating measurements of activity limitation and participation restrictions in assessments and then showing that these outcome measures are improved with treatment. Rosenbaum and Stewart (2004) state that during counselling and education of families of children with CP, therapists should relate how therapeutic activities are connected to the desired outcomes.

2.7.2 Roles of family

According to the Surveillance of Cerebral Palsy in Europe (SCPE, 2000) study, CP is a severe disability in childhood that places heavy demands on the child and their family. Similarly, Mobarak, Khan, Munir, Zaman and McConachie (2000) in Bangladesh, demonstrate that mothers of children with CP suffer from stress. This stress is associated with the behaviour impairments of the children. These behaviour impairments are those which take a lot of the mother's time such as burden of care related to lack of independence, sleep problems, bed wetting, and hyperactivity.

In Australia, in the findings of a study to explore the factors influencing adherence to a home-based strength-training programme for young people with CP, Taylor, Dodd and Graham (2004) state that the children reported emotional and physical assistance from family members, particularly parents as the main environmental factor influencing adherence. Other environmental factors identified included: availability of suitable exercise equipment, provision of exercise log book, support from the physiotherapist and programme related factors, such as number of exercises prescribed per session.

In a study about parents' experiences of stretching for children with CP in Sweden, Halvarsson, Asplund and Fjellman-Wiklund (2010) state that parents perceived that caring for the child was more time consuming than caring for an able-bodied child. These authors also state that parents expressed mixed feelings about wanting to spend time with the rest of the family but also wanting to exercise the child. This ended up causing a bad conscience and a daily stressful life for the parents. However, in a study about stress and adaptation in mothers of children with CP, Manuel, Naughton, Balkrishnan, Smith and Koman (2003) found no relationship between the child's functional status and maternal depression. This implies that maternal depression occurs regardless of the child's functional status.

Patel (2005) states that in the management of CP family-focused strategies and early intervention is required. Rosenbaum (2011) also states that the family of a child with disability plays a central role to the well-being of the child. This means that the family of the child, in particular the caregiver, needs to be actively involved in the rehabilitation process of the child. A clinical review by Rosenbaum (2003) states that parental values and goals are important in the management programme created for a child as this approach has been shown to produce effective outcomes and efficiency. Jansen, Ketelaar and Vermeer (2003) state that parents play a vital role in the transfer of skills learnt in physiotherapy from the rehabilitation

centre to the daily functioning of the child. These authors also state that parents develop more insight into impairments and disabilities of their child if they participate in physiotherapy, as this helps the parents to get a more realistic view of their child's potential in daily functioning. These authors advise that parents should not only be involved in implementing therapy activities at home, but also in setting goals, evaluating goals and deciding on content and time spent on a home programme. In addition, the authors also advice that therapists need to focus on the functioning of the child within the family when developing home programmes.

2.7.3 Roles of physiotherapy

CP is the most common disability in childhood and the most frequently encountered paediatric neurological condition in physiotherapy practice (Parkes & Hill, 2010; Glasscock, 2000). According to Singhi (2004), when started early in life physiotherapy may promote normal motor development and help prevent deformity and contractures. This author emphasises that treatment should be integrated into the pattern of daily life and individualised depending on the needs of the child and the family environment. Likewise, Sharan (2005, p. 970) states "Physiotherapy is aimed at improving infant-caregiver interaction, giving family support, supplying resources, and parental education, as well as promoting motor and developmental skills". As stated by Parkes, Donnelly, Dolk and Hill (2002) in most countries the physiotherapist is considered central to the effective management of children with CP.

Several studies have been conducted to show the effectiveness of physiotherapy techniques in the treatment of CP. Knox and Lyoyd (2002) found that gross motor and self-care skills for children with CP improved significantly following a six-week course of Bobath therapy or what is commonly referred to as neurodevelopmental therapy. However, this study had a small sample size (15 children) and there was no control group. Krigger (2006), states that the aim of neurodevelopmental therapy by physiotherapists using specific handling techniques, is to control sensorimotor components of muscle tone, reflexes, postural control, abnormal movement patterns, perception, sensation and memory.

Ketelaar, Vermeer, Hart, Beek and Helders (2001) in a study to determine effects of functional therapy program on motor abilities of children with CP, conclude that functional physiotherapy has positive effects on child's capability and independence in functional motor skills. These authors state that functional physiotherapy involves the learning of motor

abilities in functional situations where the child plays an active role in finding solutions rather than having the therapist's handling result in a solution.

Scheker, Chesher and Ramirez (1999), in a study investigating therapeutic regime using neuromuscular electrical stimulation combined with dynamic orthotic traction during day and static orthosis at night, showed the effectiveness of neuromuscular electrical stimulation and bracing in the treatment of spasticity of upper limb due to CP. However, these authors recommended that more research is required to determine whether improvement shown is due to neuromuscular electrical stimulation, dynamic traction or combination of both.

Taub, Ramey, DeLuca and Echols (2004) in a randomized, controlled clinical trial to determine applicability of constraint-induced movement therapy in children with CP, found great improvement in the use of the more-affected extremity following the three-week therapy period. The gains obtained in this period were sustained over a six-month follow-up period. The parents of the children in this study reported important developmental and socio-emotional benefits for their children.

Fowler, Ho, Nwigwe and Dorey (2001) advocate for the use of strengthening exercises in individuals with CP that have muscle weakness which may affect function. Their study results showed no increase in spasticity of quadriceps femoris muscle or any other negative effects after strengthening exercises. Similarly, Dodd, Taylor and Graham (2003) in a clinical trial to evaluate effects of a home-based, six-week strength-training programme on lower limb strength and physical activity of children with spastic diplegic CP with or without gait aids, found that strength training can increase muscle strength in children with CP. The benefits of the training were maintained for a period of three months after the six week programme ended which implies that the effects of strength training are long term. These authors suggest that strength training may also improve physical activity in the children as it had positive effects on walking, running, jumping and stair climbing. Provost et al. (2007), in a study to investigate changes after intensive body weight-supported treadmill training in ambulatory children with CP, found that body weight-supported treadmill training improved endurance, functional gait and balance. Similarly, Schindl, Forstner, Kern and Hesse (2000) found that treadmill training with partial body weight support resulted in improvement in walking and other motor abilities such as climbing stairs, standing without support, wheelchair transfer as well as sit-to-stand manoeuvres.

2.8 Spasticity

Lance (as cited by Nielsen, Crone & Hultborn, 2007, p. 62) stated that

“Spasticity is a motor disorder characterized by a velocity-dependent increase in tonic stretch reflexes (muscle tone) with exaggerated tendon jerks, resulting from hyper excitability of the stretch reflex, as one component of the upper motor neurone syndrome”

According to Graham and Selber (2003) CP results in an upper motor neurone lesion. Barnes (2001) states that the positive features of an upper motor neurone lesion such as spasticity are a result of disruption of the descending pathways that control proprioceptive, cutaneous and nociceptive spinal reflexes that are involved in motor control. These authors state that other positive features of the upper motor neurone syndrome are increased tendon reflexes, clonus, Babinsky sign, extensor and flexor spasms, dyssynergic patterns of co-contraction during movement, associated reactions and other dyssynergic and stereotypical spastic dystonias. Similarly, Bovend'Eerd et al. (2008) state that spasticity occurs as a result of lesions of the descending motor pathways.

Furthermore, Barnes (2001) states that the negative features of upper motor neurone lesion are characterized by reduction in motor activity and include muscle weakness, loss of dexterity and easy fatigue ability. These authors also state that spasticity tends to resist muscle stretch and lengthening which makes a muscle remain in a shortened position and may cause soft tissue changes. These soft tissue changes may result in contractures in the joints. Thus, maintaining range of motion in a joint actively or passively may prevent development of soft tissue contractures. Similarly, Dietz and Sinkjaer (2007) state that spastic movement disorder occurs as a result of changes in the excitability of spinal reflexes and supraspinal drive which may cause the change in muscle function and mechanical muscle properties.

Dietz and Sinkjaer (2007) state that during rest in healthy people the stretch reflex activity is low as a result of low excitability of spinal motor neurons, low muscle spindle activity, low discharge rate of afferents and pronounced presynaptic inhibition. However, during voluntary muscle contraction motor neuron excitability, spindle sensitivity and afferent discharge increase while presynaptic inhibition decreases thus, stretch reflex activity is high. These authors state that presynaptic inhibition is decreased at rest in people with spasticity which leads to high stretch reflex activity.

Spasticity is a common type of CP (Boyd, Morris &Graham, 2001; Jacobs, 2001). Spasticity affects both gross and fine motor function of a child as well as performance of activities (Beckung & Hagberg, 2002). This in effect affects how the child participates in the society in which the child lives. Graham and Selber (2003), state that the extent to which gross motor function is affected is an indicator of site and severity of the brain lesion. Spasticity is a major cause of contractures in children with CP (Farmer & James, 2001). Spasticity interferes with movement and positioning and this contributes to formation of contractures and deformities (Matthews & Balaban, 2009). However, spasticity does not necessarily result in only negative effects, for example in a paretic limb, it may result in better function by enabling walking, standing and transfer (Rekand, 2010).

According to Bobath and Bobath (1956), when spasticity increases in strength it results in abnormal postures, and if a child maintains this abnormal posture for long it results in contractures and eventually deformities. According to Graham and Selber (2003), CP is the result of an upper motor neurone lesion with features that interact to produce musculoskeletal pathology. The musculoskeletal pathology results in failure of longitudinal growth of skeletal muscle because the muscles do not relax in CP (as a result of spasticity) under physiological loading which is necessary for normal muscle growth. These same authors state that contractures of gastrocnemius and equinus deformity can be developed in children with CP because of failure of longitudinal muscle growth. Postans et al. (2010), state that contractures in children with CP are caused by shortening of the tissues in and around a joint that causes restriction of function. A number of researchers state that spasticity in some upper limb muscles like pronator teres and the wrist flexors may progress to muscle contracture at a faster rate than other muscles if left untreated (Boyd and Graham, 1999; Boyd and Graham, 1997). This may then result in deformities in the elbow and wrist.

According to Matthews & Balaban (2009) there is no standardised treatment approach for spasticity. These authors state that the treatment options for spasticity (hyper tonicity) are determined basing on whether the tone is present globally or focally. Graham and Selber (2003) state that the prevention of contractures is the main aim of management of spasticity in CP. Additionally Barnes (1998) states that the aims for treating spasticity may be to improve function, prevent complications such as contractures, relieve pain and/or improve management of the child (especially regarding hygiene). Furthermore, this author states that options for management for spasticity are threefold. The first option is physiotherapy which involves use of positioning, splinting or casting. Secondly, medical management using drugs

which include phenol blocks and botulinum toxin A. Thirdly, surgical techniques which at times includes use of intrathecal baclofen.

Several authors agree that while splinting is one strategy for managing spasticity, other strategies include: oral muscle relaxants, botulinum toxin injections, occupational therapy techniques, physiotherapy techniques, hippotherapy, neuromuscular electrical stimulation, selective dorsal rhizotomy and intrathecal baclofen (Ozer, Chesher & Schecker, 2006; Sharan, 2005). Boyd and Graham (1999) state that therapies such as Botulinum Toxin Type A (BTX-A), serial casting, splinting, physiotherapy or occupational therapy when initiated early may prevent the development of contractures, thus enhancing motor skill development. According to Krigger (2006) botulinum Toxin Type A produces a protein that blocks release of acetylcholine in order to relax muscles. Ostensjo, Carlberg and Vollestad (2005) state that the intervention chosen to treat spasticity should depend on whether the spasticity is global or focal.

Non-surgical interventions by physiotherapists to reduce spasticity include passive and active stretching, positioning, muscle strengthening exercises, facilitating the development of balance and co-ordination of movement as well as using casts and splints (Flett et al., 2009). In addition, Flett et al. (2009) recommend that non-surgical interventions are preferable for children less than six years of age so as to avoid surgical intervention risks such as over-lengthening of muscles, infection, scarring and anaesthetic complications.

2.9 Splinting: a management technique for spasticity

Splints are devices used to hold the extremities in a stable position. As mentioned above splints are used in combination with other techniques such as physiotherapy, occupational therapy, medication, neurosurgery or orthopaedic surgery. Splinting as a therapeutic technique is used for the following purposes: prevent contracture/ deformity, keep the joint in the functional position, stabilize the limb joints, facilitate motor control, decrease spasticity and protect the extremity from injury in the post-operative phase.

Literature reviewed in this section describes the evidence for using splinting in CP, the types of splints used in CP, the personnel involved in the splinting process, the role of caregivers, and the experiences of caregivers. The literature review does not discuss braces as a form of splinting for supporting the trunk/spine because they are not used in management of children with CP in Uganda.

2.9.1 Types of splints used in CP

According to various studies there are a variety of splints used in managing spasticity in CP, these include: upper limb splints, such as wrist and hand splints, cork-up splint, thumb abduction splints, spinal orthoses and lower limb splints which include foot orthoses, ankle foot orthoses (AFOs), knee braces, knee ankle foot orthoses (KAFOs), hip, and knee ankle foot orthoses (Ofluoglu, 2009; Burtner et al., 2008; Buckon et al., 2004; Steultjens et al., 2004; Knutson & Clark, 1991). Splints can be made using various materials such as plaster of paris (POP), polyvinyl chloride (PVC), bamboo, leather, metal, polypropylene, Styrofoam and wood bandage depending on what is locally available. Splints can be rigid or flexible depending on material used and the purpose of the splint. In addition, splints are designed to meet specific objectives.

According to Kuipers et al. (2009) for the arm and hand there are resting and functional splints. Dynamic lycra hand splints use a wraparound design with inserts to correctly position the thumb in a spastic hand (Wilton, 2003). Autti-Ramo et al. (2006) state that for the upper limb, the splint is chosen depending on the task that needs to be improved. A wrist and thumb brace can be used to change the hemiplegic pattern of upper limb into a more functional position of the hand (Louwers et al, 2011). The brace changes the position from thumb adduction, flexion of the wrist and fingers to a neutral position of the wrist and thumb in abduction and opposition. Goodman and Bazyk (1991) also suggest that the use of a short opponens splint reduced spasticity proximally. In the Goodman and Bazyk study after splinting, active thumb palmar abduction, radial abduction and opposition increased, as well as the grasp strength.

In a study regarding pre- and post-surgical functional analysis of the spastic hand in India, Tawde, Athani and Rege (2002) recommended below elbow cockup splint, above elbow cockup splint, long opponens splint and short opponens splint post-operatively to assist with hand function. These authors recommended the above elbow splint pre-operatively to stretch wrist and hand flexors, and post-operatively to maintain post-operative position. They recommended the above elbow cockup splint pre-operatively to stretch the elbow flexors, forearm pronators and long finger flexors and post-operatively to maintain the corrected position. They used the long and short opponens splint to maintain thumb in opposition and to create web space. Similarly, Goodman and Bazyk (1991) used a short opponens splint to increase use of the thumb in grasping of objects in a 4 year old girl with CP. The splint acted as a distal point of control to position the thumb in opposition

Ofluoglu (2009) states that in children with CP, lower limb orthoses (splints) are the most commonly used devices so as to improve walking skills. Autti-Ramo et al. (2006) state that in order to prevent equinus during walking it is advisable to use a splint that limits plantar flexion.

2.9.2 Evidence for use of splinting in CP

Studies show evidence that sustained stretching using splinting can improve the range of movement and reduce spasticity of muscles around the targeted joints in children with spasticity in CP (Pin et al., 2006; Flett, 2003). Other studies suggest that splinting in CP can be used as a long-term measure to prevent contractures from forming or recurring by stretching the spastic muscles (Postans et al., 2010; Schroder, Crabtree & Lyall-Watson, 2002). In a case report by Lundequam and Willis (2009), they report that splinting restored dorsiflexion and functional ambulation in a five-year old female with hemiparesis who was initially toe-walking. Lower limb splints may be used to provide stability to joints in a child who is learning to stand and walk. They may also be used to maintain postures or to provide support as well as flexibility (Singhi, 2004). In a study to compare gait when using solid and dynamic AFOs versus no AFO, Radtka, Skinner, Dixon and Johanson (1997) found out that the polypropylene solid AFOs and the dynamic AFOs increased stride length, decreased cadence and reduced excessive ankle plantar flexion. This infers that orthoses are beneficial particularly in children with spastic CP who have an equinus gait pattern with excessive ankle plantar flexion during stance phase of gait.

In a study by Romkes and Brunner (2002), they found that the hinged AFO changed toe walking on the hemiparetic side into heel-toe gait pattern and the dynamic AFO did not improve gait function as effectively as the hinged AFO. These authors suggested that the hinged AFO was superior to the dynamic AFO as it reduced ankle plantar flexion angle resulting in a functional heel contact. In addition, Park, Park, Chang, Choi and Lee (2004) in a study to investigate the effectiveness of the hinged AFO on sit-to-stand transfers in children with spastic CP in South Korea, found out that the hinged AFO reduced total duration of sit-to-stand transfer as well as improved angular movements of the ankle and knee joints.

Kuipers et al. (2009) state that the upper limb resting splints provide prolonged low load stretch to muscles and immobilise joints in better positions resulting in reduction of spasticity and prevention of contractures. They further state that upper limb functional splints promote upper limb function by facilitating better control and isolation of movement patterns in reach

and grasp. Louwers et al. (2011) in a study to determine the immediate effects of a wrist and thumb brace on bimanual activities in children with hemiplegic CP, found that wearing the brace improved performance of bimanual activities significantly. In this study by Louwers et al. (2011) there was great improvement in the children's ability to grasp and release objects using their hands. These authors attributed this to the fact that the brace supported the carpometacarpal joint and placed the thumb in opposition and abduction making the child's grip more powerful. Thus, it prevented the 'thumb-in-palm' posture typical in children with hemiplegic CP.

Scheker, Cheshier and Ramirez (1999) found that neuromuscular electrical stimulation combined with dynamic orthotic traction during day and static orthotic at night was effective as treatment for spasticity in children with CP. In another study, Elliott, Reid, Hamer, Alderson and Elliott (2011) showed that wearing lycra arm splints for three months resulted in faster and efficient movements in children with CP especially children that had dystonia. Kanellopoulos et al. (2009) found that treatment with botulinum toxin A combined with splinting reduced spasticity and improved function in the children.

However, despite the many uses and benefits from splinting, prolonged use of casts and splints may lead to disuse atrophy of muscles (Singhi, 2004). In a randomised controlled trial by Lannin, Horsley, Herbert, McCluskey and Cusick (2003), they showed that four weeks of hand splinting in functional resting position did not improve contracture, hand function or pain in adults with acquired brain impairment who were already receiving routine motor training and upper limb stretches. Similarly, Lannin and Ada (2011) showed that wearing a splint all night had no additional effect in reducing spasticity over usual therapy. These authors also state that splinting had little effect on activity. Splints alone may not be adequate for optimal management of spasticity, other treatment options such as serial casting, surgery and therapies may be required (Autti-Ramo, Suoranta, Antilla, Malmivaara and Makela, 2006). Furthermore, since the influence of splints occurs at the peripheral level and not at the central nervous system, the effect is temporary.

2.9.3 Personnel involved in splinting process

Splinting as a technique for the management of spasticity requires input from rehabilitation team which according to Barnes (1998) should include a physician, orthotist, occupational therapist and physiotherapist. The physiotherapist's role in the team is to promote normal motor development and prevent contractures and deformities, using techniques which include

Neuro- Developmental therapy and splinting (Singhi, 2004). Richardson (2002) suggested that the role of the physiotherapist in the management of spasticity is not only to educate the caregiver about the effects and advantages of splinting but also to educate the caregiver the physiological and biological function of the body part affected by spasticity so as to facilitate adherence. Wilton (2003) states that in a person with CP the therapeutic modalities for the hand fall within two categories, these can either affect spasticity and associated contracture or they facilitate functional use of the hand by affecting active motion and dexterity.

Occupational therapy for people with CP mainly focuses on addressing hand deformity and associated dysfunction as this may impact heavily on many aspects of daily life (Wilton, 2003). The roles of the physiotherapist and occupational therapist in splinting include assessment, prescription, designing and sometimes fabrication of the splints (Knutson and Clark, 1991). According to Knutson and Clark (1991) the role of the physiotherapist is to assess the fit and function of the splint, to ensure that it does not restrain patient's progress but facilitates function. These authors state that the designing and fabrication is done in collaboration with the orthotist or orthopaedic technologist. The role of the parent is to assist with use of the splint at home. Being a parent of a child with CP is a challenge that requires the adjustment in caregiving to the child's health and development which includes participation in home activities as part of therapy intervention (Reid et al., 2011; Davies and Hall 2005; Raina et al., 2004; Piggot, Hocking, and Paterson, 2003).

2.9.4 Role of caregivers

Raina et al. (2004) describe how the role of the caregiver is significantly different when a child experiences functional limitations and possible long-term dependence. According to Davies and Hall (2005) this role requires adjustment in caregiving to the child's health and development including participation in home activities such as home therapy programmes. Morrow, Quine, Loughlin and Craig (2008, p. 124) state that "Parents have valuable contribution to make to the team of specialised professionals caring for their child as they possess 'expert' knowledge of the child's emotional and social well-being."

Vasconcelos et al. (2009), state that caregivers directly influence performance of children. If the caregiver does not stimulate the child to use their abilities then the child becomes dependent. According to Idro et al. (2010), a lot of stress is placed on the family managing a child with severe impairment. Matthews and Balaban (2009) state that spasticity can

negatively impact on function and makes caregiver tasks such as transfers and dressing more difficult.

In Canada in a study about the health of primary caregivers of children with CP, Brehaut et al. (2004) found that caregivers of children with CP experience more mental and physical difficulties than other caregivers. These authors recommend that services should be family-centred to encourage, and address parental well-being as well as child health. They believe that better parent well-being is related to better child health. However, these authors recommend that research is needed to explore the extent to which the family-centeredness of services is associated with better outcomes for parents and their families. In addition, a study about parent-reported quality of life of children with CP in Europe, Arnaud et al. (2008) observed that lower quality of life of the child was associated with high levels of parental stress. These authors advocate for stress management as part of the intervention programs.

Schroder et al. (2002) noted that parents are important in deciding whether splints are used or not used by children. In addition, according to Sandford et al. (2008), adherence to splinting is important for a successful clinical outcome. Jain, Mathur, Joshi, Jindal and Goenka (2008) also observed that children with dedicated parents exercised and used their splints regularly, thus maintaining the correction after surgery. In developing countries, poverty, illiteracy and the paucity of health services are huge problems. Thus, physiotherapists rely on the caregivers of children with CP to continue with splinting as part of the home therapy programmes (Patel 2005). Therefore, as stated by Singhi (2004), parental education on how to handle the child at home with regards to splinting is required to ensure successful treatment.

2.9.5 Splinting: experiences of caregivers

According to Reid et al. (2011), there is a gap in literature regarding parents' reflections on experiences of raising a child with CP. A literature search found no studies regarding caregiver experiences of splinting in CP. However, one study that explored the utilisation of assistive devices at home by children with CP identified some underlying factors related to the device usage in this setting (mainly from the children's perspectives). Also, studies regarding caregivers' experiences of splinting in other childhood disabilities, such as arthritis, were found. As the experiences regarding splinting may be similar since both childhood conditions are life-long and affect the degree of the child's participation, information on these

studies is included. However, it is recognised that the reason for use of the splinting may be different.

In a study in Taiwan to explore the usability of assistive devices at home by children with CP, Huang, Sugden and Beveridge (2008) showed a low frequency of device use at home by the participating children. They attributed this to four main factors, namely: children's reluctance, mothers' perspectives, physical environmental barriers and, device-related ones. These authors state that the children used the devices more willingly at school than at home. They believed this was because children had less interaction with peers while at home and were also given more assistance at home by family so the children coped better at home, and hence had less need for assistive devices. One participant in this study stated that they felt like wearing the AFO only when going out and not at home. This child preferred to wear slippers at home despite the fact that the slippers made them stumble or fall down at times. The mothers' perspective in this study was that the children should use the assistive devices at school more than home since the children could easily get assistance at home than at school. Furthermore, many children in this study felt constricted, hot and stuffy when wearing AFOs because the material was rigid and not ventilated. This resulted in some children developing abrasions or blisters on their feet during the hot and humid summer in Taiwan.

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On the other hand, in an ethnographic study in Britain regarding families' perspectives about prescribed programmes of daily exercises, splinting and medication for children with idiopathic juvenile arthritis, Britton and Moore (2002) state that a number of parents reported that wearing the splints reduced morning stiffness of the joints of their child. Another positive experience with splint usage was reported by Davis et al. (2009) in Australia where parents stated that it was important to have splints so as to enable the child to function better.

Britton and Moore (2002) and Schroder et al. (2002) found that parents reported that the children were difficult to manage when using day time splints as the splints caused heat, discomfort and restricted mobility during play. Also according to a cross-sectional descriptive study by Kuipers et al. (2009) regarding use of splints by clients with acquired brain damage, parents noted that children refused to wear the splints during day as the children felt embarrassed to be seen with splints by their peers. In Britain, in a study by Schroder et al. (2002) about effectiveness of splinting as perceived by the parents of children with juvenile arthritis, parents reported negative reactions by children, such as disruption of sleep as a

barrier to night splinting. In addition, in the USA a qualitative study by Garwick, Kohrman, Wolman and Blum (1998) found that parents reported that limited financial resources and transportation difficulties were barriers to accessing orthotics for their children.

2.10 Splinting: factors influencing adherence

Based on the literature reviewed, there are several contextual factors that can influence adherence to splinting. According to the International Classification of Functioning, Disability and Health (WHO, 2001) the contextual factors can either be environmental factors or personal factors. According to Jain et al. (2008) inability to perform stretching exercises or wearing orthoses as instructed and not coming for regular follow up might be reasons for deterioration in children in CP.

2.10.1 Environmental factors influencing adherence

Environmental factors affecting the child with CP can influence adherence to the use of splints. According to the International Classification of Functioning, Disability and Health (WHO, 2001), environmental factors consist of the physical, social and attitudinal environment in which an individual lives. These factors are external to an individual and can positively or negatively influence an individual. In the ICF environmental factors are classified in two levels. The first level is the individual where the immediate environment of the individual such as home, workplace and school are placed. This level includes the physical and material features of the individual's environment, direct contact with family, acquaintances, peers as well as strangers. The second level is the society in which the individual lives. This includes formal and informal social structures, services and systems that impact on the individual. Organisations and services related to work environment, community activities, communication and transport services, informal social networks, and laws, regulations, rules, attitudes as well as ideologies are included in this level. Thus, environmental factors that may affect splinting include the approach used by the therapist, as well as the parents' perception of splinting as has been reported on in the literature.

2.10.1.1 Approach used by therapist

In a study done in Australia, Kuipers et al. (2009) suggest that adherence to splinting can be attributed to the use of client-centred practice by the therapists in prescribing the splints. This practise involves active participation of the client and family in the process of splinting. In another study by Schroder et al. (2002) shows that caregivers are more likely to adhere to

splinting if they have a positive relationship with the therapist and understand the reasons and importance of splinting.

2.10.1.2 Parents' perception of splinting

In Australia, Schroder et al. (2002) in a study about effectiveness of splinting as perceived by parents of children with juvenile idiopathic arthritis suggest that parents determine whether they splint the children or not, depending on the parents' perception of the usefulness of the splint and that these parents based their perception by comparing the positive and negative experiences of the children so as to decide whether or not to use the splint.

2.10.1.3 Understanding and belief of caregivers about reasons for splinting

Schroder et al. (2002) state that parents who had a strong belief in the importance of splinting continued to apply the splints despite negative experiences of the child such as discomfort, disruption to sleep and restriction to movement.

2.10.2 Personal factors influencing adherence

Personal factors of the child with CP can influence adherence. According to ICF (WHO, 2001) personal factors consist of features of an individual which are not part of a health condition. These include gender, age, race, lifestyle, habits, upbringing, social background, experience, psychological assets as well as characteristics. Thus, personal factors of the child affecting splinting may include: compliance by the child and dedication of the caregiver, the age and development of the child.

2.10.2.1 Compliance by the child and dedication of parents

A number of researchers state that in the management of CP, to ensure that therapy goals are achieved and maintained, children and the caregivers need to be dedicated to the therapy (Jain et al., 2008; Piggot et al., 2003; Boyd et al., 2001). Jain et al. (2008) found that children with dedicated parents exercised and used their orthoses and assistive devices for longer, thus maintaining correction for longer. Jain et al. (2008, p. 1001) state that "compliance of the children, dedication of the parents and proper exercises are a must for the success of any treatment in CP".

2.10.2.2 Age and development of child

Studies have also noted that as the children get older they tend to remove their splints independently, especially if they have negative experiences with the splint (Britton & Moore,

2002; Schroder et al., 2002). This implies that the reactions, age and development of the child can affect whether or not they adhere to splinting.

Summary

The literature presented in this chapter was reviewed throughout the duration of the research study. 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. I used the literature to learn more about the concepts included in the research question. 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 understand the reasons behind use and non-use of splints so as to promote adherence. Therefore, there is need to investigate the factors that affect caregivers during the splinting process in Uganda 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.

The next chapter describes the methodology used for this study.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter presents the methodology used in this study. The chapter describes the research setting, research design, population, data collection, data analysis, and ethical considerations for this study.

3.2 Research setting

This research was conducted in Uganda. Two research settings were used. Centre A is a fully equipped rehabilitation hospital located 18 km from Kampala City (the capital city of Uganda) in the Wakiso district in the central region of Uganda. The hospital is run by a non-governmental organisation offering preventive, curative and rehabilitation services for people with disabilities, with a focus on treating children with physical impairments. The hospital provides orthopaedic surgery, plastic/reconstructive surgery, physiotherapy, and occupational therapy. The hospital has an orthopaedic workshop that makes lower limb and upper limb orthotics and prosthetics at lower costs than other state or private workshops in Uganda. CP clinics are conducted once a week on Wednesdays at the physiotherapy department of the hospital.

Centre B is a rehabilitation centre located 8 km from Kampala City in the Wakiso district in the central region of Uganda. The rehabilitation centre is run by a non-governmental organisation involved in the rehabilitation of children with disabilities in Uganda. Centre B's programmes focus on orthopaedic and plastic surgery consultations, physiotherapy, occupational, and speech therapy. The centre has an orthopaedic workshop that makes orthotics and prosthetics as well as other assistive devices such as seating aids and mobility aids. The centre has an early learning centre for children with learning difficulties that opens daily. The centre has a weekly CP clinic on Fridays at the physiotherapy department.

Both centres attend to children from all over the country but access is limited by factors such as geographical barriers (poor road and transport network nationwide), economic barriers (ability to afford to pay for services), and social factors (local beliefs about causes of CP and disability generally, as well as traditional medical practices). The decision to provide a splint is made on the recommendation of the physiotherapist, occupational therapist or orthopaedic surgeon. Thereafter the child is measured at the orthopaedic workshop and issued with the splint. Follow-up reviews are carried out at the physiotherapy department or CP clinic.

3.3 Research design

A cross-sectional qualitative descriptive research design as described by Domholdt (2000) was used for this study. According to Creswell (1998) a qualitative research design enables a researcher to collect data with the aim of developing theories. This involves collecting stories of participants to determine how they personally experienced the topic under study, and is appropriate for this study since there is limited documentation about the topic under study (Creswell, 1998). A qualitative, descriptive study was used to provide a comprehensive summary in everyday terms of the caregivers' experiences during the splinting process (Sandelowski, 2000). A qualitative cross-sectional descriptive research design was considered the most appropriate as this would enable the researcher to systematically collect data about the experiences of the caregivers at a specific time (Domholdt, 2000). In this study, the qualitative approach was also used because of its advantages as it will help to highlight the participants' experiences by examining participants' words and convey the situation as experienced by the participants (Maykut & Morehouse, 1994). The qualitative approach was used to describe the experiences of caregivers of children with CP regarding splinting in Uganda. Description involves discovering what is happening or present during the splinting process based on the responses and focusing on what respondents share (Bernard & Ryan, 2010).

A quantitative research design was not considered appropriate because quantitative research seeks to confirm hypotheses about phenomena (Creswell, 1998). Also, since there was limited data concerning splinting experiences of caregivers of children with CP there was a need to use qualitative research methods to identify the variables that can then be used in a quantitative research study (Bernard, 1995). In addition, considering the objective of this study, to describe the experiences of individuals, a qualitative research method was considered more appropriate (Denzin, 2000). A quantitative research method would have been considered if the objective was to quantify variation, predict causal relationships or describe the characteristics of a population (Creswell, 1998). Therefore, the researcher found it more appropriate to use qualitative research design for the study. There was no quantitative research method implemented in the study.

3.4 Study population and sampling

The study population included all the caregivers attending the two centres with the children with CP.

3.4.1 The sample

Purposive sampling was used to select caregivers from each centre. According to Babbie (1995) purposive sampling is used to select participants with particular characteristics and is based on the researcher's knowledge of the population, its elements and research aim. Purposive sampling was used with the aim of obtaining participants that would provide rich information about their experiences regarding splinting (Sandelowski, 2000). Participants for this study were selected from the databases of both centres.

Inclusion criteria

- The caregiver of a child who had been attending the CP clinic in 2010 as shown by the name of the child in the attendance/appointment register at the centre.
- The caregiver of a child (age ranges 3- 17) with CP

The sample size was 24 caregivers. They were selected to ensure a rich diverse experience would emerge in the data. This included that there were caregivers of children with differing types of CP (quadriplegia, hemiplegia, diplegia, athetosis). There were caregivers of children who received different types of upper limb and lower limb splints. The caregivers were also selected to ensure they came from a variety of different cultures and tribal groups in Uganda and that they were from different educational and social backgrounds. There was one male caregiver who is the father of the child, two were grandmothers to the children and twenty one were the mothers of the children.

3.5 Data collection

The researcher went for familiarization visits to both research settings a month before beginning data collection. Once permission was granted by the management of the two institutions, the researcher contacted the heads of the physiotherapy departments and orthopaedic workshop at centres A and B so as to select participants for the study. The databases of both research settings were reviewed to identify children with CP who received splints in 2010. Based on the database, 50 children with CP received splints at centre A in 2010, while 80 children with CP were fitted with splints at centre B in the same year. The medical files for these children were retrieved and the telephone contacts for their caregivers obtained. The caregivers were then contacted telephonically and requested to participate in the study. As there were no children fitted with a brace for the trunk/spine, they were not

included in the study. Of the 130 children only 50 caregivers could be telephonically contacted. However of these only 30 caregivers accepted to participate in the study. Those that were willing to participate were then asked regarding the location where they would like the interviews to be conducted. All caregivers preferred to have the interviews at their homes. A timetable for the interviews was then drawn up. Financial costs (transport costs to individual caregiver's home) and time constraints (there was limited time for data collection) made it difficult to interview all 30 caregivers, it was only possible to interview to 24 caregivers.

Prior to the interviews the participants were explained the process and given the information sheet (Appendix A). Informed written consent was then obtained using consent form (Appendix B). In-depth interviews, as described by Skinner (2007), were used to obtain detailed information from the participants. The interviews were held at the caregivers' homes in a quiet, private comfortable room and free from disturbance. The average duration of interviews was one to two hours, depending on when data saturation was achieved. The interviews were audio-taped and the researcher also took notes of the proceedings during the interviews as recommended by Mays and Pope (1995). The information noted included observations about hesitations and facial expressions of the participants as well as the general mood of the participants.

An interview guide (Appendix C) was used for the interviews. This was developed by the researcher based on the research aim. The interview guide was used so as to ensure that the researcher covered the same topics with each interviewee (McNamara 1996). Using an interview guide with semi-structured questions is of an advantage as it lets the respondents speak out in their own words but ensures that data can be systematically examined for patterns in the nature and consequence of the experience (Bernard & Ryan, 2010). The questions in the guide sought to draw out caregivers' experiences with the splinting programme for their children. The questions in the interview guide covered the following areas:

- A. Caregivers' positive and negative experiences.
- B. Caregivers' opinions about splinting.
- C. Caregivers' beliefs about splinting.
- D. Description of how caregivers splinted the children.

E. Challenges caregivers had with splinting.

F. Solutions devised by caregivers for the challenges faced.

G. Caregivers' expectations from splinting.

H. Suggestions the caregivers had to improve the splinting process.

The researcher did not necessarily ask everyone the same questions in exactly the same way. A demographic questionnaire (Appendix D) was used to obtain demographic data of the participants and the children.

Language

Before using the interview guide, it was translated from English into Luganda which is the language understood by all majority of the caregivers. One Luganda language specialist translated the guide. This guide was then used for the study.

3.6 Trustworthiness

The processes of credibility as described by Guba (1981) were employed. Credibility was established mainly through member checking and peer debriefing. Member checking was used during interviews; the researcher fed back participants responses to them to refine, rephrase, and interpret. Debriefing sessions were also held with the supervisor. According to Guba (1981) to ensure credibility, the researcher developed familiarity with the participating organisations by paying preliminary visits to the settings before data collection begun. To further increase credibility, the researcher adopted appropriate, well recognised research methods. The researcher also used tactics to help ensure honesty in participants such as giving participants opportunities to refuse to participate, encouraging participants to be frank at the beginning of the interviews, as well as using to probes to obtain detailed data. The researcher (a physiotherapist) may have had prior interactions with some of the caregivers. This may have created an inherent bias toward positive feedback about service providers, especially rehabilitation therapists. This was prevented by informing participants of freedom to choose to withdraw at any time and that the information obtained will only be used for research purposes.

Credibility was also increased by employing methods as described by Graneheim and Lundman (2004) such as: choosing participants with various experiences, showing representative quotations from transcribed text and peer review. To further enhance

trustworthiness, the researcher also used reflective journaling (Ortlipp, 2008). This allowed the researcher to document their experiences, opinions and thoughts throughout the research process. This process enabled the researcher to gain new insights into the complexity of qualitative inquiry (Watt, 2007).

To ensure transferability, the researcher has provided background data to the context of the study and also provided a detailed description of phenomenon in question to allow comparisons to be made (Guba, 1981). For confirmability purposes the researcher will recognize the shortcomings in the study's methods and the potential effects but also admit the researcher's beliefs and assumptions (Guba, 1981). The researcher also created and adhered to a coding scheme so as to increase validity of the study (Hsieh & Shannon, 2005). A pilot interview to determine the participant's understanding of the questions in the interview guide was not carried out. However, during the course of the interviews the researcher had to rephrase some questions for purposes of clarity.

3.7 Data analysis

The tape recordings from the interviews were transcribed verbatim by a research assistant. This was cross-checked by the researcher. The transcribed scripts were then translated from Luganda to English by a professional translator. The researcher (who is fluent in both languages) reviewed the translated transcripts to ensure that the meaning was retained. The researcher compared the field notes written during the interviews, notes in the reflective journal with the transcribed scripts to ensure all data were included.

The researcher used content analysis as described by Sharma (2008) to analyse the transcripts. Sandelowski (2000) states that: "Qualitative content analysis is the analysis strategy of choice in qualitative descriptive studies". Similarly, Elo and Kynga's (2008) recommend that content analysis can be used to describe the phenomenon under study. Content analysis consisted of reading the transcripts several times before coding the data, and then formulating themes or categories from these codes. According to Hsieh and Shannon (2005) content analysis helps the researcher gain a richer understanding of the phenomenon of experiences of caregivers and involves distilling words into fewer content related categories (Elo & Kynga's, 2008).

Inductive content analysis was used to obtain categories from the data (Elo & Kynga's, 2008). Coding was done in multiple stages over time and involved back and forth movement between whole and parts of the texts (Graneheim & Lundman, 2004). The initial coding

process was an open coding process (Elo & Kynga's, 2008). The researcher closely read and coded every line of each interview transcript. Transcripts were then condensed; a process of shortening but texts still maintaining the core or content (Graneheim & Lundman, 2004). During this process, the texts were coded and concepts were highlighted and labelled. Inductive analysis which involves interpreting patterns found in data and deciding what they mean was used to obtain themes from the data (Bernard & Ryan, 2010). According to Sandelowski (2000), content analysis involves modifying themes to accommodate new data and new insights to the data. Thus, based on this initial analysis, subsequent coding took place in the manner of constantly comparing the current transcript with previous ones to allow the emergence of categories (sub-themes). As the coding proceeded, additional sub-themes emerged.

Qualitative content analysis involves interpretation of both manifest and latent content (Sandelowski, 2000). Manifest content are the actual words or phrases stated by the participants while latent content is the meaning behind the words and the phrases. Hsieh and Shannon (2005) define content analysis as a research method for subjective interpretation of text data using systematic processes of coding and identifying themes. These same authors identify three types of content analysis, namely: conventional, directed and summative content analysis. They further state that conventional content analysis is recommended when existing literature on a phenomenon is limited as this method of analysis enables the researcher to gain information from the respondents without imposing preconceived categories or theoretical perspectives. Hsieh and Shannon (2005, pg. 1286) state that: "content analysis offers researchers a flexible, pragmatic method for developing and extending knowledge of the human experience of health and illness." However they also state that the challenge with content analysis is the failure to develop a complete understanding of the context which may result in inaccurate representation of the data. But, this can be overcome by techniques such as peer debriefing, prolonged engagement, persistent observation, triangulation, and member checks (Guba, 1981). Since no quantitative data was collected, there was no analysis quantitatively.

3.8 Ethical considerations

Ethical clearance to conduct the study was obtained from Senate Ethics Committee at the University of Western Cape. Approval to conduct the research was obtained from the Uganda National Council of Science and Technology and the Mengo Hospital Research Review committee. The researcher requested permission to access the medical records of the children

from the Chief Executive Officer at the hospital and from the Executive Director of the rehabilitation centre.

Participants were informed and assured of freedom to choose to withdraw at any time and that the information obtained would only be used for research purposes. Consent to audio-tape the discussions and to take pictures of some of the children was requested. In addition, to ensure confidentiality the researcher would not use the participants' names or any information that can make them identifiable when documenting the findings; the researcher would keep the data collected in a locked cabinet only accessible by the researcher. The data collected would be locked up for a period of six months after the study is conducted and written up then destroyed. A copy of the summary of the findings will be made available to the physiotherapy departments at the research settings. The researcher advised one of the participants to take the child back for review at the centre where the child received the splint, as the child had developed wounds but was not getting adequate treatment from the nearby clinic.

Summary

This chapter discussed the research methodology used in the study. A qualitative exploratory research design employing in-depth interviews was selected for the study. Two centres were used for data collection. Twenty-four (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 next chapter describes the findings of the study.

CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter presents the findings of a study in Uganda that explored the experiences of caregivers of children with spastic CP regarding the splinting process. **Table 4.1** (Appendix E) shows the demographic profile of the caregivers and the children. During analysis the researcher analysed the data into six themes concerning experiences, namely: caregivers' expectations and beliefs; acquisition of splints; knowledge and skills; attitudes to splinting; compliance and benefits of splinting. The theme expectations and beliefs of the caregivers is presented first as these may influence the experiences of the caregivers. This is followed by a description of the other themes of caregivers' experiences. Transcribed verbatim excerpts from the caregivers are quoted in such a way that the language of the informants is preserved while ensuring their anonymity.

4.2 Demographic profile of participants and children

Twenty-four (24) caregivers of children with spastic CP were interviewed. Of these, 21 are mothers, 1 is a father and 2 are grandmothers to the child. The children were from age ranges three to 17 years. Ten are caregivers of children who have spastic hemiparesis/ hemiplegia, 11 are caregivers of children who have spastic quadriplegia, and 3 are caregivers of children who have spastic diplegia.

4.3 Themes

The themes and sub-themes that emerged are shown in **Table 4.2**.

Table 4.2 Themes and subthemes

Themes	Sub-themes/ Categories
1. Caregivers expectations and beliefs	Caregivers expectation of healing the child
	Caregivers expectation that the splint will lead to change in child's limb
	Caregivers expectation of no further improvement

	Caregivers beliefs in divine intervention for splinting to work
2. Acquisition of splints	Caregivers experiences of time involved in obtaining a splint
	Caregivers experiences of costs in obtaining a splint
3. Knowledge and skills	Caregivers experiences of getting information and skills
	Caregivers experiences of applying the splints
	Splinting precautions
4. Attitudes to splinting	Attitudes of caregivers towards the splint
	Attitudes of children to own splint towards their own splint
	Attitudes of other children and community towards the child wearing a splint
5. Compliance	Caregivers application of the splint
	Trusting others with application of splints
	Frequency and duration of splinting
	Challenges experienced during splinting that affect compliance
6. Benefits	Benefits experienced by caregivers
	Suggestions for improvement to splints made by caregivers

4.4 THEME ONE: CAREGIVERS' EXPECTATIONS AND BELIEFS

This theme included four sub-themes. Caregivers spoke about their expectations of healing the child; the expectation that the splint would make a change to the child's limb; the expectation that there would be no further improvement; and beliefs in divine intervention linked to splinting.

4.4.1 Caregivers expectation of healing the child

11 caregivers expected splinting to heal or cure their child. One caregiver, a father of a four year old girl with hemiplegia, expected the child's wrist to be healed because he believed she was on treatment. Unfortunately the wrist did not heal. He believes it did not heal because he only used the splint for a short duration (five months) as the splint was causing the child's wrist to swell. Another caregiver, a mother of a seven year old boy with hemiplegia, expected the splint to cure his arm. This is because the child's arm had improved since she had started splinting and she was now able to straighten the wrist which she could not do before. Other caregivers stated:

I believe it will straighten his arm. I am hoping for his arm to get straight or get cured. (Cg E, child 7 years)

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 (Cg G, child 7 years)

I believe it will heal my child's foot because the foot is already better now. (Cg F, child 9 years)

Some caregivers reported that they expected their children to become like other "normal" children (children without disabilities). Some of the caregivers for example stated:

I expected that maybe one day the splints would help him stand, walk that was my hope. (Cg B, child 6 years)

I expect them to make him normal again. He is now walking so soon he will be okay again. (Cg L, child 5 years)

4.4.2 Caregivers expectation that the splint will lead to change in the child's limb

4.4.2.1 Improve function

Caregivers expected the splint to lead to improvement in function as mentioned by this caregiver:

I expected my child's hand to get better such that she could do most of the house chores and then maybe have the therapist look at the leg. (Cg H, child 11 years)

4.4.2.2 Straighter limb

Caregivers expected the limbs to be straightened with the use of the splint as stated by this caregiver:

I was expecting it to straighten those muscles. (Cg A, child 7 years)

4.4.2.3 Reduce spasticity

One caregiver expected the splint to reduce spasticity by relaxing the child's muscles as stated below:

I believe that the splint can help soften the stiff foot. (Cg P, child 15 years)

4.4.2.4 Improved function

Eight caregivers expected splinting to bring about a change or difference in the functional ability of the child's limb. The change expected was for the splint to correctly position the limb which would result in improvement in limb function. A mother of an 11 year old girl with hemiplegia expected the splint to make the child's hand better so she could do more household chores. Other caregivers mentioned that they expected improved function:

I believe that the muscles will get straight and the leg will get better or straight. I expect them to straighten the legs, perhaps even help him to walk. (Cg C, child 11 years)

Even the leg of that side was not alright, but these days when I see him walking, he walks better not like a disabled person. My hope is for the arm to get alright, maybe start holding some items. (Cg E, child 7 years)

4.4.3 Caregivers expectation of no further improvement

On the other hand two caregivers however did not expect the splints to bring about more improvement in the child. A mother of an 8 year old girl with spastic quadriplegia stated that she had expected the splints to make the child better which they had done (since the child is now able to crawl), so she was not expecting them to make any further changes as stated below:

I no longer expect them [the splints] to work. Except for crawling at least she can crawl and go wherever she wants. (Cg J, child 8 years)

Another caregiver of a 12 year old who was no longer using the splint said she did not expect any more improvement:

I expected them to straighten his legs which they have done, so I don't expect anything more. (Cg M, child 12 years)

4.4.4 Caregivers beliefs in divine intervention for splinting to work

Four caregivers' stated that they believed that for splinting to help it depended on divine intervention:

I believe that I should do my best, and then leave the rest to God. I also did not expect this good progress. (Cg J, child 8 years)

When God wishes my child will get better and start walking. Because the feet are straight now, he is only left with starting to walk. (Cg S, child; girl, 6 years)

One caregiver indicated that improvement in the child while splinting depended on the caregiver's faith in God.

All in all one just has to have faith in God. Because the splint in itself, I don't see it as a form of therapy. It has no immediate change or miracle with its use like you would take malaria tablets or other medication that can cure something. (Cg D, child 4 years)

A grandmother of a seven year old boy did not indicate the need for divine intervention but saw a link to their traditional healing methods. She compared splinting to treatment received from traditional (local) bone-setters who strap sticks with herbal medicine around a limb to "heal" various ailments.

I think it [the splint] is helpful in the same way that a local bone setter would set bones and tie some sticks on them. Even this splint can act in the same way or do the same purpose. Because long ago I saw traditional bone-setters use such things to straighten bones. (Cg A, child 7 years)

4.5 THEME TWO: ACQUISITION OF SPLINTS

Two sub-themes pertaining to the acquisition of splints for their children were identified. These included the caregivers' experiences of the time involved in obtaining a splint and the experiences of the cost involved in obtaining a splint.

4.5.1 Caregivers experiences of time involved in obtaining a splint

All caregivers described how their child was assessed by either a physiotherapist or occupational therapist at the CP clinic in the therapy department to determine if the child required a splint.

The therapist told me that I have to buy the arm splint to enable the child's fingers to straighten. (Cg H, child 11 years)

When the child was then referred to the orthopaedic workshop, by the therapist who had assessed them, the orthopaedic technician took the measurement for the splint. More than three quarters of the caregivers' (79%) spoke of how measuring for the splint involved a Plaster of Paris (POP) cast being applied on the limb and that this cast was then removed after a few minutes.

We were measured and given a date to pick it. (Cg G, child 7 years)

I took her for measurements; they put a cast on her leg to measure the size of the splint. I was given a date to return for the splint and I found them ready when I went back. (Cg U, child 5 years)

13 caregivers mentioned that the measurement did not take long. After the measurement, the child was given an appointment date to return when the splint has been made. At this appointment the splint was fitted and taken home. 16 caregivers stated that it takes between one to three weeks before the child can get fitted:

We did not get the splints immediately. We had to wait for a week. (Cg K, child; boy 4 years)

We had to wait because there were many people in line waiting for similar splints so we got ours after 3 weeks. (Cg R, child 9years)

One caregiver, a mother of an 11 year old girl with quadriplegia, mentioned that the splints were not ready on the appointed date and they had to go back several times before the child was fitted with the splint. Unfortunately, this mother has two other children with CP and she had to travel with all three children to the service provider each time. The mother complained about the transport costs to the service provider being high:

Several times when we went to pick them they were not ready. Transport costs are high and I had to take all three children. But eventually we got the splints. (Cg I, child 11 years)

Another caregiver, a mother of a seven year old boy with hemiplegia, stated that she had not had time to go and collect another pair of splints. The splints that the child was using were no longer fitting:

I even have to go and pick another set; it is just that I have not found time yet to go to the health centre. (Cg G, child 7 years)

4.5.2 Caregivers experiences of costs involved in obtaining a splint

Prior to being measured, 17 caregivers mentioned that they have to pay for the splints or show proof that the splint would be paid for, in the instance that the child was being sponsored by an organisation. One caregiver stated that:

I had to pay for the splints and then she was measured and later on given the splints. (Cg T, child 10 years)

Caregivers mentioned that there are costs involved in obtaining the splints. The costs they mentioned included: costs for transport, the splint, and paying the centre for treatment. All of the caregivers commented that the costs involved were expensive. Some caregivers commented that:

What I have observed is that the splints are expensive. We pay for them, it is so costly. It cuts into our income (Cg D, child 4 years)

Transport costs are high and I had to take all three children. (Cg I, child 12 years)

I have been planning to go back and consult the health workers about the splints not fitting the child any more but have no money yet for transport or to pay for consultation. (Cg T, child 10 years)

11 caregivers were assisted by either public or private organisations to pay for the costs of the splints and services. 7 caregivers stated that they registered with either public or private organizations (depending on whichever was available in their community) that assisted them to pay the costs for the splint. 11 caregivers also suggested that they still needed organisations

to continue assisting them to get new splints when needed. Some of the caregivers' responses included:

An organisation paid for the splints so I did not pay anything. (Cg R, child 9 years)

An organisation paid the cost of the splints, and then I went to the orthopaedic workshop for measurement of the child. Then two weeks later we got the splints. (Cg V, child 10 years)

I do not pay for services at the hospital. (Cg F, child 9 years)

One caregiver whose child was given an upper limb splint (hand splint) stated that they were advised that the child would need a splint for the leg (AFO) as well, but because of a lack of funds and time (since the caregiver has to work) they never went back to get the AFO. The caregiver stated that:

I was then asked to bring the child back to see the progress of the arm, which is when they would decide to work on the leg too. But due to the child's condition, lack of funds and time, I am not able to go back to the centre regularly. (Cg H, child 11 years)

Another caregiver, a mother of a five year old boy with quadriplegia, requested to have the prices of the splints adjusted such that the splints are not so expensive. Other caregivers stated:

We only got challenges in the beginning because of money but after joining OVC [Orphaned and Vulnerable Children] we have not found any challenge. (Cg O, child 17 years)

We joined a project that helps such children (OVC). So we did not pay money, the project paid for the splint. Yes, we will continue using the splint if the organization continues supporting us. (Cg G, child 7 years)

4.6 THEME THREE: KNOWLEDGE AND SKILLS

This theme includes the subthemes of the experiences of how the caregivers got information and learnt skills; and the precautions linked to splinting.

4.6.1 Caregivers experiences of getting information and learning skills

All caregivers identified their sources of information regarding splinting. The caregivers also explained who taught them, as well as the skills they learnt on how to apply the splint. One

caregiver mentioned that the therapist had informed her that the splint would help to straighten the child's legs:

According to the therapist, splinting is helpful to keep the legs straight. One cannot do exercises all the time. Splints can help with that. (Cg C, child 11 years)

4.6.2 Caregivers experiences of applying the splints

Concerning the skills learnt, all caregivers reported that when the child was fitted with the splint they were instructed on how to use the splint. The caregivers stated that they were instructed by either a physiotherapist, occupational therapist or an orthopaedic technician on how to use and apply the splint. Caregivers stated:

The therapist taught me the day the child was to be measured. (Cg F, child 9 years)

The therapist taught me the day the child was given the splint. (Cg G, child 7 years)

It was the orthopaedic technician in the workshop who taught me. (Cg K, child 4 years)

I was taught by the therapists at the centre. They told me to I had to splint the child every day to help straighten the feet. (Cg U, child 5 years)

However, two caregivers suggested that they needed to be taught more thoroughly how to apply splints when at home as stated below:

Parents should be taught how to use the splints. (Cg U, child 5 years)

I suggest that the other parents who are given the splints should use them properly without fail. (Cg A, child 7 years)

4.6.2.1 Exercises

Eight caregivers mentioned that they were instructed on the exercises that need to be done prior to splinting the child's limb. Others mentioned that they had to position the limb correctly before splinting. Caregivers' comments included:

The therapist taught me that I needed to exercise the foot first before putting on the splint. (Cg F, child 9 years)

The therapist taught me to first position the leg or arm correctly, do exercises and then place the splint. (Cg G, child 7 years)

I was taught that I first had to straighten the legs and foot. When splinting I am to start with the foot and then eventually the leg. (Cg W, child 3 years)

4.6.2.2 Function

Another caregiver, a mother of a five year old boy with quadriplegia, stated that she was instructed to splint the child when he was going to use the standing frame. She mentioned that she was instructed that the child needed to use open shoes with the splints, and also instructed to stand the child in the frame for 30 minutes and then remove the child.

4.6.2.3 Children taught about splints

Eight caregivers mentioned that the child was involved in the discussions regarding the use of the splint:

The child was encouraged to walk when splinted. He was included in the discussion. (Cg M, child 12 years)

They explained to us together with the child. Yes, the child was involved. He is 17 years old so he can understand. (Cg N, child 17 years)

While other caregivers mentioned that child was not included in the explanation:

The child was not explained to, the therapist only explained to me. (Cg F, child 9 years)

The child doesn't hear or talk so they just explain to me. (Cg W, child 3 years)

The child does not understand much, so it is me the parent who takes responsibility to understand what is being explained. (Cg J, child 8 years)

4.6.2.4 Crying

One caregiver stated that she was advised to take off the splint if the child cried:

"But we were advised by the health worker that if he cries, we put them off for a while until he gets back in a happy mood then we try again." (Cg S, child 6 years)

A mother of a six year old child with athetoid CP, stated that she was advised to remove the splints when the child cried, but that she should also continue trying to use the splints until the child got used to the splints.

4.6.2.5 Replacement

Another caregiver stated that they were advised that the splint may need to be replaced after some time. This is because there was need to observe the child and the outcome of splinting. Also, as the child grew the child may outgrow the splint and require another splint.

I was then asked to bring the child back to see the progress of the arm, which is when they would decide to work on the leg too. (Cg H, child 11 years)

4.6.2.6 Hygiene

A mother of 17 years old boy with hemiplegia reported that she was told to keep splint clean, as well as the child's arm.

4.6.3 Splinting precautions

A mother mentioned that she was told that if they had any problem with the splint, she was to go back to the clinic. This caregiver had to go back after a week of using the splint, to be taught how to apply the straps correctly, because the child developed an unspecified problem at the wrist.

18 caregivers mentioned precautions they took during splinting, these included making sure the limb was dry before splinting, using socks and ensuring the splint was not fastened on too tight. Caregiver responses included:

I first straighten the legs, make sure the legs are dry then splint him. (Cg K, child 4 years)

At first I thought the splint was small but the therapist told us not to tighten it so much; when we did that there was no more sores caused. (Cg N, child 17 years)

Four caregivers mentioned that they were advised to use socks with the splint so as to avoid the splint from causing the child pressure sores:

I was told that before I splint him, I had to dress him in socks then straighten the legs then apply the splint. (Cg Q, child 10 years)

Also he needs some socks, trousers for the splints not to cause bruises. (Cg C, child 11 years)

4.7 THEME FOUR: ATTITUDES TO SPLINTING

The sub-themes identified were the different people's attitudes towards the splints. The attitudes were those of the caregivers themselves, the child, other children, and the community members where the child lived.

4.7.1 Attitudes of caregivers towards the splint

19 caregivers stated that they liked the splints, were happy with the splints and did not find problems with the splints even though they did experience some difficulties while using the splints.

I like the splints and have no bad experience except that I have to remove the splints every two hours to bend the legs a little. (Cg I, child 11 years)

I am so happy. I can see a big difference in my child. The health worker told me that he [the child] can even now go to school. (Cg L, child 5 years)

Seven caregivers commented that splinting was good since it assisted to maintain the children's limbs in a good position when the caregivers were not moving the children's limbs or when the child is walking.

Splinting is helpful to keep the legs straight. One cannot do exercises all the time. Splints can help with that. Also he needs some socks, trousers for the splints not to cause bruises. (Cg C, child 11 years)

The splints are good especially if the child is walking, he can wear them with shoes. They were made very well. (Cg W, child 3 years)

4.7.2 Attitudes of the children towards their own splint

Caregivers reported that the children have different reactions to their splint. Sometimes these were positive, sometimes negative, and sometimes ambiguous, or that the child's attitude had changed over time. Eleven out of 24 caregivers reported that the child did not like the splint. The caregivers suggested this because the splint either caused the child discomfort or pain. Caregivers made statements such as:

He cries; he doesn't like the splint especially when I try straightening his legs. He does not like the splints. (Cg C, child 11 years)

The problem is the child does not like it [the splint] at all; he gets tired quickly whenever you try to make him do exercise. You find that the child has failed to get used to the splint and exercises. (Cg G, child 7 years)

One caregiver said the child complained that splint was tight.

I have not found anything negative only that when we put on the splint, she [the child] complains that it is too tight. (Cg F, child 9 years)

Five caregivers mentioned that sometimes there is stigma attached to the splints and the children did not like the splint because people made fun of them when splinted and the child then removes the splint.

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. (Cg E, child 7 years)

I would not have any problems with the child's splint but the problem the child does not accept the splints. It [the splint] embarrasses her among her friends who make fun of her. (Cg H, child 11 years)

However, one caregiver reported that the child liked the splint and complained of pain when the splint was removed, for example, during bath time or when cleaning the splint. The caregiver stated that:

When he removes the splint, the hand pains him because he has got used to the splint supporting his weak arm. For instance when he has to bathe or clean the splint, he complains of pain. That's the problem we have. (Cg N, child 17 years)

Another caregiver stated that it took the child a while to get used to using the splint. The child initially did not like the splint but eventually got used to it. The caregiver mentioned:

Like any other normal person who is using something for the first time, he was not used to the splints but eventually he got used to them. Then he stopped crying, whenever we made him wear it, he used to cry before. (Cg B, child 6 years)

4.7.3 Attitude of the other children and community towards the child wearing a splint

Caregivers said that the people in the neighbourhood where the child lived had a variety of attitudes towards the child wearing the splint. Some of the people in the community liked the child wearing the splint, while others did not. Some of the other children laughed at the child,

while other children helped the child when splinted. One caregiver (Cg K) of a four year old child with hemiplegia mentioned that other children were initially afraid of the child because the child got the disability later in life but had now started getting used to the child. Another caregiver stated:

Some children like her in the splints; they help her walk when in them. But the child does not want to wear the splints. Some neighbours like her in the splints; some do not, others encourage me to use the splints regularly even if the child cries. (Cg J, child 8 years with quadriplegia)

Six caregivers stated that other children and people make fun of the child, or stare at the child; so the child does not want to use the splint. Caregivers stated:

They [other children] sometimes make fun of him. So, sometimes he refuses to walk because children laugh at him but we have to use the splint by all means. (Cg F, child 9 years)

They [other children] make fun of him. They say he has two extra arms and legs. (Cg G, child 7 years)

I like the splints 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. (Cg H, child 11 years)

The neighbours do not say anything; the other children just stare at him. (Cg, X, child 5 years)

One caregiver reported that the family and the child were discriminated against as stated below:

I have found a big challenge with this child. Whenever I take him out of the house in his wheelchair and splints, people gather around and stare. Even the landlord wanted to chase us away because he was told we have something strange in the house. (Cg W, child 3 years)

Another caregiver, a mother of a 17 year old teenager with hemiplegia, mentioned that neighbours were initially doubtful of the splint being beneficial to the child and that other children used to stare at the child. However, the splint had now straightened his hand except

that the child had not begun holding items yet. This change in the child's hand had made the neighbours' attitudes towards the splint more positive.

Four caregivers mentioned that they would educate the people about the child and the splint in order to stop them laughing or staring at the child. Caregivers stated:

I just stop them [other children] from laughing at the child. I do not ask them why, they are just children, and what do they know? (Cg F, child 9 years)

I tell them [other people] to stop [telling the child that he has one arm and leg] and he hears me telling them. (Cg, G, child 7 years)

4.8 THEME FIVE: COMPLIANCE

Sub-themes under this theme included: caregivers' experiences of using the splint; how caregivers apply the splints; trusting others with application of splints; frequency and duration of splinting; challenges experienced during splinting that affect compliance.

All caregivers described how they applied the splints at home, the duration of applying the splint on the child; who applied the splints; the difficulties experienced during the process and suggested solutions.

4.8.1 How caregivers apply the splints

One caregiver mentioned that when she was at home she found that applying the splint was a slow process that took time as stated:

To splint her, one has to first correctly position the wrist so it takes time splinting her because you cannot straighten the wrist at once. You have to do it slowly. So to splint her I have problems with straightening the arm because it is time consuming. (Cg D, child 4 years)

Caregivers explained that before applying the splint they have to position the limb correctly. 19 caregivers mentioned that they have to stretch the limb and dress the child in socks (for those with lower limb splints). Caregivers stated:

As the health worker explained, I first insert the thumb then the other fingers and then you tie the straps. (Cg A, child 7 years)

To splint; I would undo the straps, straighten the wrist and fingers. This is because the wrist and fingers would be stiff in flexion and then splint her according to the way it [the splint] was made. (Cg D, child 4 years)

I straighten out his wrist, insert it in the splint then I fasten the straps. (Cg E, child 7 years)

The splints have straps at the feet and the legs. I strap the feet first then the legs. I place the child in the standing frame after that. (Cg X, child 5 years)

14 caregivers mentioned that they have to coerce the child to accept to be splinted as stated by one caregiver:

Ok, I place him in lying position, I speak to him, something like; put on the splints and we go, he relaxes. Without coercing him, he can never accept to wear the splints. (Cg B, child 6 years)

Others mentioned that they may even have to use force to apply the splint:

To splint him, I first unfasten the straps of the splints, and then I force the knee into extension. After that, I put the leg straight then I tie the straps of the splint around the knees and later tie the other straps. (Cg C, child 11 years)

4.8.2 Trusting others with application of splints

18 caregivers stated that the children needed assistance to apply the splint, while four stated that the children could put on their own splints without assistance. 17 caregivers indicated that they were the only ones who could be trusted to splint the child. A mother of a six year old boy with quadriplegia stated that sometimes the child was not splinted, because she (the mother) was not at home to apply the splint. On the other hand, three caregivers stated that they trust other relatives to apply the splint. One mother stated that she only trusts the child's father:

When I am away, he does not use the splint if the father does not help splint him. (Cg G, child 7 years)

Another caregiver stated that they trust the child's sisters to apply the splint as stated below:

The sisters also help him at times when am not around, they know what to do. (Cg P, child 15 years)

Some caregivers also mentioned that they trusted the child to do it on his own:

He splints himself. (Cg N, child 17 years)

He splints himself. (Cg P, child 15 years)

4.8.3 Frequency and duration of splinting

19 caregivers' stated that they put the splint on the child either during the day time or night time:

I splint the child daily. (Cg I, child 11 years)

I use the splint for the legs during day. (Cg J, child 8 years)

After I shower him in the morning, I do the exercises and then splint him all day. (Cg L, child 4 years)

One caregiver, a mother of a nine year old boy said she applies the splint during night only because the child complained of pain when she put the splint on during day:

During the day she complains of pain, so I remove it for a while, but in the night she sleeps with it. (Cg F, child 9 years)

A grandmother of a seven year old grandson stated that she initially started splinting the child during the day time. She stated that the child used to remove the splint and when she asked the therapist what to do, the therapist advised her to change her routine and splint the child during the night time (when the child slept) and then child stopped removing the splint.

One caregiver stated that they applied the splint for some hours during the day:

He spends like an hour in the splint, depending on the time I am home. (Cg Q, child 10 years)

The other caregivers mentioned that they put the splint on the child during both day and night time. Caregivers that splinted the child during both day and night mentioned that they removed the splints when the child went to bathe or to eat or to aerate the limb:

He used to put it on day and night. But once in a while we would remove it for the child to get fresh air. (Cg K, child 4 years)

Yes, she wears them every day especially at school. At home she can remove them when she is going to bathe, after that she puts them back on. (Cg T, child 10 years)

Another caregiver stated that she used the splint four times a week:

No, we use the splints maybe four times a week. On the days I would not be home I would come back and the maid says she has not splinted the child. (Cg X, child 5 years)

Two caregivers also mentioned that they did not splint the child when the child was ill:

Yes I splint daily, except when she is sick because she sometimes faints and falls. (Cg I, child 12 years)

If the child falls ill, she cannot use the splint. When she is weak, you cannot use the splints. (Cg J, child 8 years)

On the other hand, one caregiver stated that not having a specific duration of how long the splint was to be used was also a challenge. This caregiver stated that they were advised to use the splint for as long as the child accepted to remain with the splint, they were not instructed on specific duration for applying the splint.

4.8.4 Challenges experienced during splinting that affect compliance

Caregivers expressed that they encountered a number of challenges during the splinting process. Challenges mentioned are described below.

4.8.4.1 Splint not fitting child

17 caregivers identified that one of the challenges was the child outgrowing the splint or the splint not fitting the child as a result of the child growing. The challenge was that once the child outgrew the splint, they have to return to the service provider to obtain another splint. Caregivers made comments such as:

I have not found anything negative only that when we put on the splint, she complains that it is too tight. (Cg F, child 9 years)

The splints stop fitting him. (Cg G, child 7 years)

The child outgrows the splint, so we have to replace them whenever the therapist says the splint no longer fit him. The child would outgrow the splints, then he cries when you try to splint him because the splints would be small. (Cg X, child 5 years)

Four caregivers also commented that they modified the splint in case of the splint not fitting well.

The splint gets smaller as he grows and they give him another one. (Cg F, child 9 years)

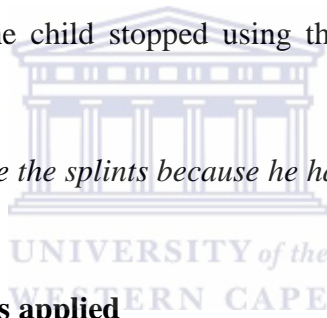
As she grows, we go back to the centre and they advise us according to how the leg has progressed. The health worker decides what to do next to change the size or the type of splints. (Cg U, child 5 years)

However, the thumb does not fit in the splint because it is too deformed so we use a rubber band to fix it. (Cg H, child 11 years)

There are not many negative experiences only that the splints are getting small and tight on the feet so we use a sponge. (Cg T, child 10 years)

One caregiver mentioned that the child stopped using the splint when it no longer fit as mentioned below:

These days he does not use the splints because he has out-grown them, they are small. (Cg, G, child 7 years)



4.8.4.2 Child cried when splint is applied

13 caregivers stated that the child cried when splinted and that this made the caregiver uncomfortable. Eight caregivers stated that once the child cried they decided to remove the splint as a solution.

No challenge except when it stays on for a long time, the child cries a lot. (Cg I, child 12 years)

We found challenges with the longer splint because he cries whenever he wears them. (Cg B, child 6 years)

The child cries a lot whenever we splint him and the child gets tired easily. (Cg G, child 7 years)

When I splint her, she cries a lot. (Cg U, child 5 years)

Most times he cries when I splint him. What I do not know is if that is because of pain in the muscles. However, if he spends a long time in the splints, he stops crying but at the start he cries. (Cg W, child 3 years)

He cries when splinted. (Cg X, child 5 years)

Some of these caregivers stated that they removed the splint(s) or stopped using the splint(s) so as to stop the child from crying. They stated that they re-applied the splint after the child had stopped crying:

I also feel uncomfortable while seeing him cry to that extent that I remove them, to enable me finish my home chores with the view that after I am done, I would make him wear them later. (Cg B, child 6 years)

I remove them when she starts crying. (Cg U, child 5 years)

4.8.4.3 Pain

Out of the 24 caregivers, 10 caregivers mentioned that the splint made the child uncomfortable and caused the child pain. The caregivers attributed the pain to the stretching effect of the splint on the muscles:

This splint when he wears it; it straightens the wrist and causes pain, but he has to be strong and wear the splint. (Cg N, child 17 years)

I do not find any problems with splinting, only that sometimes when I splint him, he complains of arm pain. (Cg E, child 7 years)

Am not sure but I think they cause him pain at times and he is not comfortable. (Cg B, child 6 years)

4.8.4.4 Splint causing discomfort

Some (four) caregivers mentioned that the splint made the child so uncomfortable that the child would not agree to perform activities. A mother of a six year old boy with spastic quadriplegia mentioned that the child was in so much discomfort that he even failed to eat when splinted. She mentioned that she had to remove the splints before the child would agree to eat. The caregiver stated:

One cannot do anything else, but only attend to him at that time. He even fails to eat. But we try and splint him. I also feel uncomfortable while seeing him cry to that extent

that I remove them, to enable me finish my home chores with the view that after I am done, I would make him wear them later. (Cg B, child 6 years)

4.8.4.5 Child removing the splint

Four caregivers mentioned that the other challenge was that the child removed the splint. Caregivers stated that the child uses the splint mainly when the caregiver is around. If the caregiver goes away, when they return they find that the child has removed the splint:

No problem except for the occasional times when the child removes it. I used to use it and found it helpful but the owner (child) would remove it. (Cg A, child 7 years)

If I am not around at home him, when I get back at times I find when he has removed it. But, when I am around he wears it. (Cg E, child 7 years)

One caregiver, a father of a four year old girl with hemiplegia, stated that he thinks the child removes the splint because the splint appears heavy for the child.

4.8.4.6 Muscle stiffness

Two caregivers mentioned that the difficulty with applying the splint was the spasticity:

The challenge I find when splinting her is that sometimes the muscles are stiff and wrist is in flexion. (Cg D, child 4 years)

He gets stiff as I try to splint him. (Cg B, child 6 years)

One caregiver mentioned that he stopped splinting the child as a solution to the challenge of spasticity and splint application being time-consuming:

About stiffness of the wrist and fingers, it would waste so much time while splinting her so I stopped using it. (Cg D, child 4 years)

4.8.4.7 Illnesses

Two caregivers mentioned that the child being ill was a challenge. For example, a father of a 4 year old girl with hemiplegia stated that his daughter has sickle cell disease which affects the use of the splint. This is because whenever he would splint the hand, it would get swollen, so he stopped using the splint. The other caregiver stated:

I have found challenges using the splint because when the child has intellectual disability, the splint does not help the child. (Cg G, child 7 years)

4.8.4.8 Difficulty travelling with child and splints

Three caregivers reported that it was a challenge travelling with the children and the splints because the splints require storage space. It is also difficult to travel with the children while they are wearing the lower limb splints. The splints do not bend at the knees so the children need more space for the legs.

The problem with the splints is that you need your own car. It's so difficult to travel with them using public transportation because the splints don't bend, they are straight and long. (Cg B, child 6 years)

Other challenges include taking him to the hospital and school. (Cg E, child 7 years)

One caregiver stated that as a solution to the challenge of transporting the child to the centre they stopped going and would wait for community workers to come to their home.

I stopped taking him there [the centre] and wait for the community workers to come home. (Cg E, child 7 years)

4.8.4.9 Difficulty getting someone to look after other children when going to hospital or centre

Six caregivers stated that they had difficulty with getting people to look after the other children who remain at home when they go to the centre. A caregiver stated:

The challenge is getting someone to stay with them [other children]. Most adults work so it is difficult to convince someone to spend the day caring for your children, but somehow I manage. (Cg F, child 9 years)

4.8.4.10 Splint causing ulceration

Three caregivers stated that the splints had caused ulceration or wounds. A caregiver stated:

The problem with the splints is that they cause him ulcerations. He gets ulcerations near the thighs whenever he has the splints. Even on the heels, he also gets ulcerations. (Cg C, child 11 years)

Seven caregivers suggested that the splints need to be padded so as to protect the child's skin as stated below:

Yes, I need to be helped with putting some padding material on the splints and also to make the splints longer since they are now short. (Cg T, child 10 years)

Maybe they add on something to protect the skin, but me I do as the health worker instructed me to. (Cg A, child 7 years)

4.8.4.11 Splint causing warmth

Four caregivers mentioned that the splint makes the limb feel warm. This is because perspiration accumulates in the splint since the splint does not allow sweat to escape or evaporate. A caregiver stated that:

The negative experience was sweating inside the splint as he played. (Cg K, child 4 years)

One caregiver mentioned that the child removed the splint to overcome the feeling of warmth:

Even if I try and splint her, whenever she feels hot or warm, she removes it herself. (Cg D, child 4 years)

4.9 THEME SIX: BENEFITS OF SPLINTING

Under this theme there are two subthemes: the benefits of splinting the caregivers experienced; and the suggestions for improvements that the caregivers made.

4.9.1 Benefits experienced by the caregivers

The caregivers mentioned a number of benefits of splinting they had experienced so far. These included a reduction in spasticity;

4.9.1.1 Reduced spasticity

15 caregivers mentioned that the splint reduced spasticity and thus relaxed the limb.

The splints have made him more relaxed. (Cg W, child 3years)

The splint helps us, the foot no longer bends, and ok also with exercises the foot is now soft. (Cg B, child 6 years)

4.9.1.2 Increase in joint mobility

The reduced spasticity in effect reduced the stiffness of joints of the limb allowing an increase in joint mobility. Four caregivers stated that:

His legs were so stiff but now they are better. (Cg Q, child 10years)

Before splinting the arm used to be stiff and bent but ever since we started splinting, I can straighten the arm. (Cg E, child 7 years)

Because before splinting, he couldn't straighten his fingers, he could fold them but now he can straighten them. This shows that the splint is helping. (Cg A, child 7 years)

The legs never used to bend but now they bend. Also the legs are equal in length now. (Cg I, child 12 years)

4.9.1.3 Apparent improved strength

Ten caregivers felt that the splint made the limb stronger as stated by this caregiver:

There was a great difference because before the leg was completely helpless but with the splint and exercise, the leg got strength. (Cg P, child 15 years)

Even the muscles are a little bit stronger than before he started using the splints. (Cg C, child 11 years)

He gets stronger; I think the splints support him somehow. (Cg K, child 4 years)

4.9.1.4 Improved function

14 caregivers mentioned that the splint helped the child to do more functional activities:

I find that using the splint is good because before the child couldn't try moving his hand but ever since they gave me that splint I did as I was instructed, he can move his hand now and the leg he couldn't move it before he can move it now. (Cg A, child 7 years)

One caregiver stated that the splint corrected the position of the limb allowing the child to participate in play and dressing:

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. (Cg F, child 9 years)

Two caregivers mentioned that the splints had improved the child's ability to perform activities.

The splints have helped to straighten his leg; ... The splints are good because they make the legs straight which enables him to stand without falling. (Cg C, child 11 years)

He moves faster now unlike before. They help the foot not to drop. (Cg G, child 7 years)

4.9.2 Suggestions for improvement to splints made by caregivers

Nine caregivers made suggestions on how to improve the splints. They stated that making functional splints and splints with hinges, especially for the lower limb, would make using the splints easier.

4.9.2.1 Hinged splints

One caregiver suggested that the children who have splints for the whole lower limb are given hinged splints. In particular with hinges at the knees as she thought this would enable the child to wear them at night.

I request that we get those with hinges in the knees which are easy to bend so that he can also use them in the night. (Cg M, child 12 years)

4.9.2.2 Dynamic splints

One caregiver suggested a dynamic splint is needed for the hand to enable the child to do functional activities while wearing the splint.

I suggest they make an appliance that can help the fingers more flexible so that the fingers can move and he can play. That can help make him better. (Cg G, child 7 years)

4.9.2.3 Boot

One caregiver suggested that a splint needs to be more like a shoe where the splint is incorporated into the shoe:

That is why we would want to change to a shoe-like splint. He doesn't feel comfortable with this present splint. (Cg O, child 17 years)

Another suggestion was to make a splint that could be adjusted as the child grows.

4.9.2.4 Lightweight splints

One caregiver suggested making lighter splints:

If only they can make a lighter one [splint], because this old one is heavy. It should be lighter that is the answer. (Cg D, child 4 years)

Summary

This chapter described the experiences of caregivers of children with spastic CP in Uganda regarding splinting. The six themes identified were: Theme One Caregivers' expectations and beliefs; Theme Two Acquisition of splints; Theme Three Knowledge and skills; Theme Four Attitudes to splinting; Theme Five Compliance and Theme Six 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. It took a period of between one to three weeks to obtain the splint. They were initially measured for it at the CP clinic at the therapy department and then referred to the orthopaedic workshop at the centre. However, at times the splint was not ready and the caregivers had to return several times before the child got fitted. This splinting process could be very time-consuming for the caregivers. 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 of the children were included in these discussions. 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. They find it difficult to trust

anyone else to do this. Most caregivers splint either during day or night time and a few or 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.



CHAPTER FIVE: DISCUSSION

5.1 Introduction

In this chapter, the findings from experiences of caregivers of children with spastic CP regarding splinting are discussed according to the main themes that emerged. This discussion aims to answer the research question: “What are the experiences of caregivers of children with spastic CP regarding splinting?”

During analysis the researcher categorised the data into six themes concerning experiences namely: caregivers’ expectations and beliefs; acquisition of splints; knowledge and skills; attitudes to splinting; compliance; and benefits of splinting.

5.2 Caregivers expectations and beliefs

Most of the caregivers’ expectations of splint wearing ranged from the child getting healed, cured or becoming “normal” to the splint causing a change in the child’s limb or no improvement. Expected changes in the limb were straightening of the limb, relaxing the spastic muscles and as a result improvement in function. Some caregivers who had already experienced an improvement in their children did not expect any further improvements from splinting. Other caregivers believed that the outcome of splinting was dependent on divine intervention or compared it to treatment by traditional bone setters. However, the caregivers could not explain the reasons behind their expectations or beliefs. This may have been because of poor caregiver understanding of the aims or principles behind splinting, as well as inadequate knowledge of the nature of CP being caused by brain damage or that it leads to permanent motor difficulties. No documented literature regarding expectations of caregivers concerning splinting was available to compare the findings.

Traditional bone setting is an old practice found almost in all communities of the world. Bone setters are a category of traditional herbalists who treat bone fractures and dislocations with traditional herbs. Bonesetters use the application of a traditional splint at the fracture site. The traditional fracture splints are made from locally available materials such as bamboo, cane, and palm leaves. These materials are knitted together to form a mat-like splint which are usually tightly wrapped round the fracture site. The treatment period for the fracture varies with the severity of the fracture or dislocation. In Uganda, the patients who attend traditional bone setting centres prefer these herbalists because they are thought to be cheaper compared to western medical care and, more importantly, to promote quicker healing of the fracture.

The practices of bone setters are recognized in Uganda. It is therefore important for physiotherapists to learn about beliefs in relation to traditional medicine. This will give the physiotherapists an insight into what some caregiver's beliefs are, as well as guide therapists to use these beliefs to encourage adherence to splinting and other therapy techniques. During training for physiotherapists, it is important to also have training related to communication as well. This training should include techniques for better communication such as how to listen and comprehend caregiver/ child expectations, and methods of how to explain difficult medical issues or procedures to caregiver/ child. This will be beneficial when it comes to explaining splinting procedures and may result in caregivers having more realistic expectations from splinting.

5.3 Acquisition of splints

The findings in this study indicated that it took a period of between one to three weeks to be issued with a splint; however at times the splint was not ready and the caregivers had to return several times before the child got fitted. To some caregivers this was a great effort travelling long distances to the orthopaedic workshop. As mentioned in the findings it is very difficult for caregivers to find anyone to look after children at home so they must bring all of them to the centre each time.

Caregivers in this study indicated that the costs involved in splinting were expensive. In a study in Bangladesh, Mobarak, Khan, Munir, Zaman and McConachie (2000) state that caring for a child with physical disability may result in limited resources for the family as they have to spend on services for the child as well as transport costs to access the services. These authors recommend that "economic empowerment of such families may, thus, be an essential factor in successful interventions" (Mobarak, Khan, Munir, Zaman and McConachie, 2000 p. 431). According to Davis et al. (2009), having financial resources to cater for children, pay for therapy and for equipment such as splints, is important for parents and plays an important role in the quality of life of children with CP. In this study, the fact that caregivers commented that they needed support to purchase these splints, may explain why some caregivers did not go back to the service providers to obtain replacement splints as stated by this caregiver:

I have been planning to go back and consult the health workers about the splints not fitting the child any more but have no money yet for transport or to pay for consultation. (Cg T, child 10 years)

This finding is similar to the findings of a study, by Garwick et al. (1998) in the USA, to identify recommendations from urban families, from three urban ethno cultural backgrounds, for improving care of children with chronic conditions, where parents reported the lack of financial and transportation resources as a barrier to accessing equipment and treatment.

In Uganda, it would be useful if physiotherapists could get information about the different organisations that can provide funding so as to make splinting available for all that need it. This information is not easy to access mainly because there is no networking between government and non-governmental organisations. However, if physiotherapists working in an area could network with the different organisations in that community to find out what is available; perhaps this would improve on service provision as well as avoid duplication of services within the community.

5.4 Knowledge and skills

Medical and health care professionals are the main source of information for parents (Cavallo, Feldman, Swaine and Meshefedjian, 2009). In a study to investigate experiences of parents of children with CP in Canada to identify areas in which health care providers and educators could improve practice, Reid et al. (2011) state that giving caregivers' information regarding diagnosis and prognosis is vital for the child's family. Likewise, in a qualitative cross-sectional study in Australia, Morrow, Quine, Loughin and Craig (2008) suggest that providing families with information about both good and bad experiences of an intervention may facilitate informed decision making. Similarly, Camden, Swaine, Tetreault and Brodeur (2010) state that paediatric rehabilitation should include features to increase information sharing with families. Furthermore, in a study about family needs of parents and youth with CP, Palisano et al. (2009) found that a high percentage of parents expressed needs for information about current services, community resources and supports. This is similar to the findings by Halvarsson, Apslund and Fjellman-Wiklund (2010) in a study about parents' experiences of stretching for children in CP, where the parents expressed a need for scientific knowledge regarding stretching from the physiotherapists.

However, in the current study, when questioned, the caregivers mentioned that they were taught how to use the splints by therapists (physiotherapists and occupational therapists), as well as by orthopaedic technicians on the date of the fitting of the splints. The majority of the caregivers interviewed in this study described the skills they were taught, but did not report any good or bad experiences related to splinting skills that they were provided with. They

were taught about exercises prior to applying the splints; about what to do if the child cried; when to go for a replacement splint; how to look after the splint hygienically; and the precautions they needed to be aware of. It thus appears that caregivers were mainly taught skills of applying the splint but not informed sufficiently about what to expect from splinting. It was also evident that the caregivers were not involved in making the decision about whether the child would benefit from splinting or not. It appeared as if it was solely the decision of the therapist, and the caregivers were not included as a partner in making the decision whether to splint the child's limb or not. Caregivers were expected to agree and comply with the therapists' decision regarding splinting the child. Although some children were involved in learning about the splints they were also not part of the decision-making process. It is therefore not surprising that some caregivers seemed to have high expectations from the splinting while others did not understand the importance of splinting the child. This is as a result of not being informed adequately of what the purpose of the splint was and what to expect from splinting.

In addition, in this study most of the caregivers could remember the therapists' verbal instructions regarding their child's splinting schedule. This is similar to the findings of a study by Kuipers et al. (2009) in Australia to investigate factors that influence clients' utilisation or on-utilisation of upper limb splints. In Kuipers et al.'s study, all clients (except one) could recollect therapists' instructions with regard to the splint-wearing schedule.

In the current study, there was no data to imply that caregivers were shown visual demonstrations to teach them how to use splints, neither were they given any printed instructions to take home. Most of the caregivers in the current study had a low literacy level. This may have affected how they perceived or understood the instructions from the physiotherapists. It may have been better if the physiotherapists had given the caregivers instructions in form of visual images depicting the instructions as well as information about the splinting process and challenges that may be experienced.

5.5 Attitudes to splinting

The findings indicate that the attitude of most caregivers in the study was positive towards splinting. Most caregivers viewed the splints as beneficial and necessary for their children. Thus, caregivers were willing to assist their children in obtaining the splints. Splint usage at home was mainly influenced by the caregivers' expectations and beliefs, as well as the

attitude of other children and neighbours. In instances where the caregiver's expectation had been achieved, the caregiver made the decision to stop using the splint as mentioned below:

I no longer expect them [the splints] to work. Except for crawling at least she can crawl and go wherever she wants. (Cg J, child 8 years)

Where the expectations were not yet met the caregiver continued to splint the child. However, the attitudes of other family members were not fully explored, mainly because it was the caregivers who reported their experiences and perceptions of family members' attitudes.

In the current study the attitude of most of the children, as reported by the caregiver, was that they did not like the splints. Only one child liked the splint and cried when the splint was removed. This is different from the findings by Huang, Sugden and Beveridge (2009), in a study to understand children's perspectives regarding device use in school in the UK, where they found that children had a high willingness to use their devices (which included AFOs). However, the authors state that the high frequency of device use may be linked to the fact that the children in this study believed that their devices were accepted by their peers and teachers which was not the case in the current study.

Findings in the current study indicate that other children and neighbours reacted differently to the child wearing the splints. Some liked the child regardless of the splint; others feared the child because of the splint; others helped the child to use the splints; while others ridiculed the child because of the splint. It was noted that if the splint caused negative reactions from other children and neighbours towards the child, the child stopped using the splint especially if the child was old enough to remove the splints themselves. One caregiver stated that:

I would not have any problems with the child's splint but the problem is the child does not accept the splints. It embarrasses her among her friends who make fun of her. (Cg H, child 11 years)

The findings indicate that in an environment where the children feel they are treated or looked at differently because of the splints, the children are less likely to use the splints. Therefore, the reaction and attitude of the people in the child's community influence how the child uses the splint. In a study about family and peer issues among adolescents with spina bifida and CP in Minnesota in the USA, Blum, Resnick, Nelson and Germaine (1991) found that devices such as wheelchairs and mobility aids (crutches or walkers) run a high risk of setting these youth apart from their peers. In this study, despite the fact that splints are not

mobility aids, they are devices that are externally worn so they are visible to the non-user. Thus, they can also run a risk of setting the children who use them apart from those who do not. According to Lawlor, Mihaylov, Welsh, Jarvis and Colver (2006), difficult attitudes include people staring or being patronizing. In the current study caregivers mentioned that the neighbours stare at the child and this may explain why the children do not like wearing the splint. Thus, the contextual factors (societal and attitudinal environment) are influential factors determining whether splints are used or not.

Physiotherapists can help with stigma reduction in Uganda by creating awareness and sensitization about various disability issues in the community. The physiotherapists can also act as advocates for inclusion for people with disabilities in the local communities. Splinting can be one of the topics for discussion when carrying out disability awareness and sensitization meetings in the community. Awareness and sensitization about various disability issues in the community can be done using mass media such as the local radio stations, television stations as well as print media (newspapers, newsletters, posters). Improving awareness about disability, its causes and management options (including splinting) may reduce on social stigmatization of people with disabilities, particularly those using splints and other assistive devices such as crutches, white canes and wheelchairs.

5.6 Compliance

In the current study, all caregivers described how they applied the splints at home, the duration of applying the splint on the child; who applied the splints; the challenges experienced during the process and suggested solutions.

One of the caregivers in the current study stated that applying the splint is time consuming. This is understandable since the caregivers have other duties to perform at home besides assisting the child to apply the splint. It may help with adherence if physiotherapists suggested to caregivers to apply the splints when performing other activities with the child, such as after the child has finished bathing or feeding. This may help the caregivers include assisting the child with splint application into their daily activities which may improve on adherence to splinting. In addition, caregivers can be taught by the physiotherapists' techniques to use so as to convince the child to use the splint. These techniques may include play or relaxing positioning techniques.

There is evidence implying that the caregivers were not given a specific duration for when to splint the child as stated by this caregiver:

It cuts into our income and the other thing is that the splints have no specified duration for when the person will be using the splint or whether it will heal the limb.
(Cg D, child 4 years).

The caregivers were instructed to splint the child but it is not clear whether they were instructed to either splint during the day or night time. It is also not clear if caregivers were instructed on a specific duration for how long to apply the splint.

She used to wear the splint day and night until the child refused to use it anymore.
(Cg H, child 11 years)

Yes, I do not remove them at night, only in the day for her to crawl a little bit. (Cg I, child 11 years)

The caregivers also need advice regarding what they can do regarding splint application when the child is ill. It is important that the physiotherapists give caregivers specific instructions regarding splint usage and duration of splinting as this may help encourage adherence.

In the current study, caregivers mentioned that they did not trust other people to apply the splints. This is understandable considering that most of the caregivers were the mothers of the children. In Uganda, the role of the mother is to take care of children and as such the mothers' felt it was their sole responsibility to assist the children with splint application. It is important for physiotherapists to educate the mothers of children with CP on the importance of getting help from other family members. This is important as it will ensure there is someone to assist the child with applying the splint, but it may also help reduce on the mother's level of stress since she does not have to worry when she is not available to assist the child.

Caregivers in the current study mentioned a number of challenges experienced during splinting. The challenges can be divided into three groups: those associated with the splint, those associated with the social environment and those associated with the child. Those associated with the splint included: the splint being expensive, the splint not fitting the child, the splint causing the child pain and discomfort such as the splint causing warmth and ulcerations. The social environmental challenges included difficulty in travelling with the child and the splints, as well as difficulty getting someone to attend to other children when taking their child with CP to the service provider. Those associated with the child included: the child crying when splinted, child removing the splint and muscle stiffness. Other

challenges are when the child is ill and the child failing to perform activities when splinted. It is therefore evident that the caregivers are faced with many challenges.

The most commonly mentioned challenge was that of the splint causing the child pain or discomfort. The solution to this challenge for most caregivers was to remove the splint. This may explain why many of the caregivers do not adhere to the splinting instructions. Caregivers cannot be expected to continue splinting the children if the splints cause the child pain or discomfort. These findings are similar to those of a study by Schroder et al. (2002) where they identified negative aspects of splinting, such as the splints being uncomfortable and restrictive to movement. In addition, these authors state that parents mentioned that the splints also interfered with the children's functional development and play. Furthermore, it was reported that children did not like the splints because the splints were made from hard material and also because the splints made the children "stand out" (Schroder et al. 2002, p. 77). According to a study by Britton and Moore (2002), wrist splints caused embarrassment, and day splints made the child unmanageable since sitting on chairs and wearing clothes became difficult. Also according to these authors, parents stated that exercising the child was painful and boring as it was monotonous and repetitive.

In the current study, the social environment challenges included difficulty travelling with the child while using public transport. This is similar to the finding by Lawlor, Mihaylov, Welsh, Jarvis and Colver (2006), in a study to ascertain from families of children with CP the features of social, attitudinal and physical environments which facilitate or restrict participation. They found that barriers to participation included problems with access to public transport. Likewise, Masasa, Irwin-Carruthers and Faure (2005), in a study about the knowledge of, beliefs about and attitudes to disability in South Africa, found that using public transport is a challenge experienced by families of children with disabilities. The challenge of transport is likely to result in the caregivers not taking their children back to service providers for follow-up assessment or treatment.

In the current study, caregivers also mentioned that splinting was expensive. This is similar to the findings by Lawlor, Mihaylov, Welsh, Jarvis and Colver (2006), where they found that parents have additional expenditure when having a child with a disability since parents have to spend money on special equipment such as assistive devices, as well as house and car adaptations. These authors also found that having a child with a disability may result in

reduced family earnings as one or both parents left work, or worked part-time in order to look after the child with a disability.

Furthermore, the daily splinting process was also time-consuming. The issue of splinting being time consuming was expressed by several caregivers, and as one caregiver stated:

To splint her, one has to first correctly position the wrist so it takes time splinting her because you cannot straighten the wrist at once. You have to do it slowly. So to splint her I have problems with straightening the arm because it is time consuming. (Cg D, child 4 years)

This is similar to the findings by Britton and Moore (2002) in a study about insiders' experiences of families that care for a child with juvenile idiopathic arthritis where time spent on a home exercise programme was considered to consume a significant portion of their time. In this study the authors found that 75% of families spent between 2 hours 40 minutes and 4 hours 40 minutes weekly to perform the home exercise programme. In addition, in a study to explore the parent's experiences of carrying out stretching as a home programme in Sweden, Halvarsson, Asplund and Fjellman-Wiklund (2010) found that caring for a child with disability was perceived to be more time consuming than caring for an able-bodied child. Furthermore, these authors also noted that parents expressed mixed feelings as they were torn between spending time with the rest of the family and having to exercise the child with disability.

Literature reviewed suggested environmental and personal factors may contribute to adherence to splinting. The environmental factors identified included: approach used by therapist and parents' perception of splinting (Kuipers et al., 2009; Schroder et al., 2002). The personal factors identified were compliance by the child and dedication of parents, understanding and belief of caregivers about reasons for splinting, the age and development of the child (Kuipers et al., 2009; Jain et al., 2008; Piggot et al., 2003; Britton & Moore, 2002; Schroder et al., 2002; Boyd et al., 2001).

In the current study some of the factors that may influence adherence to splinting included: caregivers' expectations and beliefs of splinting, attitudes to splinting, compliance by the child, the age and development of child. In the current study; three out of 24 caregivers mentioned that the child was no longer using the splint. Reasons caregivers stated for the children not using the splint included: the splints were uncomfortable or caused the children

pain and sores, as well as the children's embarrassment about the appearance of the splint. However in this study, the reasons for not using splints were not explored in depth. The challenges experienced during splinting may help to explain why the caregivers do not adhere to splinting instructions. However, it was noted that one caregiver in this study continued to splint the child despite the splints causing sores on the child's skin.

In the current study, the reasons caregivers stated for the children for not using the splint are different from those identified by Phillips and Zhao (1993) in a study to describe general patterns of device use and abandonment in USA. In the Phillips and Zhao (1993) study the factors identified were: lack of consideration of user opinion in device selection, easy device procurement, poor device performance and change in user needs or priorities. The difference in these findings may imply that users of similar devices in different environments may have different reasons for use or non- use of devices. This is stressed in the ICF for effective outcomes the environment an individual lives in needs to be considered when planning or executing an intervention.

Physiotherapists need to know the challenges that caregivers experience during splint application so that they can help caregivers avoid the challenges, or alternatively to guide caregivers about how to handle or overcome the challenges once challenge is experienced. For instance, physiotherapists can advise caregivers to monitor the child's skin for signs of pressure from the splint, or sores. Physiotherapists should also be able to give caregivers an official telephone contact number for the caregivers to contact them in case they experience challenges. Physiotherapists can also ensure that the splints are all padded and comfortable for the child before issuing for home use so as to avoid the child disliking the splint.

5.7 Benefits of splinting

In this study, positive experiences from splinting included: there was reduced impairment including reduced spasticity and increased mobility in the joints, the child's limb became straighter, one splint corrected a foot deformity. Additionally there was a reduction in activity limitations where the splints improved the functional abilities of the child including one child's walking. This has similarities to some of the benefits identified by parents in a study by Schroder et al. (2002), which were that the splints prevented development of contractures and deformities, reduced pain during and after sleep, and that functional upper limb splints provided support during handwriting. In the current study the benefits from splinting were different for each child. Thus, it is important for physiotherapists to explain to each and every

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.

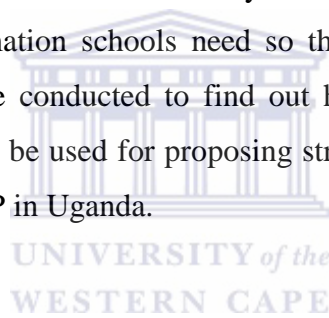
6.4.4 Service providers

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
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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



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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!!



UNIVERSITY *of the*
WESTERN CAPE

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

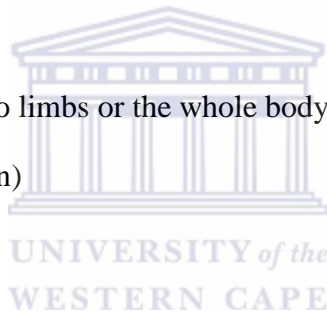
Spasticity can affect one limb, two limbs or the whole body.

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



UNIVERSITY of the
WESTERN CAPE

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

A handwritten signature in blue ink, appearing to read 'P. Josias'.

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



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

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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).

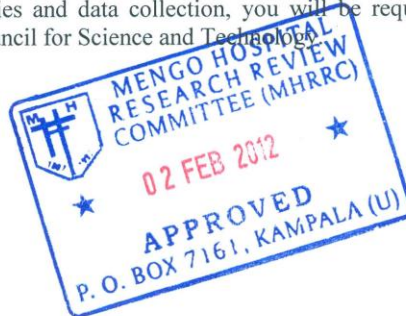
You are reminded to provide this committee with timely progress reports and final report on completion of the research project.

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. Damulamba Edick

Prof. M. Kawooya
Chairman (MHRRC)



DEPARTMENT OF PHYSIOTHERAPY

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South Africa
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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

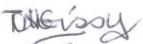
I am a post-graduate student in the Physiotherapy Department at the University of the Western Cape, South Africa. For my degree for the MSc Physiotherapy I need to complete a research project.

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



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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: Coslance Kekihembo



A Member of LCD Global Alliance

DEPARTMENT OF PHYSIOTHERAPY

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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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DEPARTMENT OF PHYSIOTHERAPY



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

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 olina 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 eddoozi lyante kulutambi bwenaba nenyigira mu kunonyereza kuno
- Sikiriza kutwala ddoozi 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 egiyinda okuva mu kunonyereza kuno?

Okunonyereza kuno tekuliwo kuganyula muntu ssekinomu nga gwe, naye ebinavamu bijja kuyamba anonyereza okweyongera okugukuka 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 okuva amagezi oba okuwabula mu ngeri y'okukozesa ebyambazibwa mu magulu oba emikono gy'abaana ngabali ewaka. Era ebinava mu kunonyereza bijja kuyamba abajanjabi 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 kujanjaba 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 kujanjaba kw'omwano wo.

Bwemba nina ebibuuzo?

Okunonyereza kuno, kuleteddwa Christine Tusiime omuyizi mu ssetendekero lya Western Cape. Bwoba oline 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 kundagiriro 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 ebagega:

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!!!