

**BARRIERS EXPERIENCED BY PARENTS/CAREGIVERS OF CHILDREN
WITH CLUBFOOT DEFORMITY ATTENDING SPECIFIC CLINICS IN
UGANDA.**

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A mini-thesis submitted in partial fulfillment of the requirements for the degree of
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Abstract

Clubfoot is the most common congenital structural deformity that leads to physical impairments in children in many poor developing countries. Inadequately treated or neglected clubfoot has been found to be a common cause of physical disability globally among children and young growing adults. Many children are referred to the clinics for treatment but some parents do not comply with the treatment regimen which requires attending for consecutive treatment sessions. The **purpose** of this study was to investigate barriers to treatment attendance parents/caregivers of children with clubfoot encounter in complying with clubfoot treatment during the plaster casting phase in Uganda. The objectives of the study were to identify: (i) parents' knowledge of clubfoot and its treatment; (ii) parents' roles during the plaster-casting stage of clubfoot treatment; (iii) the difficulties parents experience in attending all treatment appointments; (iv) associations between compliance to treatment and parents' knowledge about clubfoot, parents' experience of communication with the clinician, and (v) the difficulties parents experience in attending all treatment appointments. **Methodology:** The study was conducted at the Talipes Clinics of Mbarara Regional Referral Hospital and Mulago National Hospital in Uganda. The study utilized quantitative methods using a cross-sectional descriptive survey. One hundred sixty seven parents/caregivers were recruited in the sample. A structured, self-administered, closed ended questionnaire was used to collect data. Statistical Package for Social Science (SPSS) was used to analyze the data. Descriptive statistics and Pearson chi-square were used to analyze the data. The **results** indicated that all parents understood their role in the treatment of clubfoot during the plaster-casting phase and 74% of parents understood the consequences of not following the treatment regimen. Sixty seven percent of parents indicated that they did not know about clubfoot and its treatment before their child was diagnosed. Sixty-seven percent of parents indicated that they had poor communication with the clinicians; and 64% of the parents indicated that the clinicians did not give them a chance to talk about their problems. The factors that affected parents attending regular treatment appointments included: (i) high transport costs; (ii) lengthy travelling distance; (iii) poor social/family support; and (iv) poor communication between the parent and the clinician. The study

found a significant association between compliance and transport costs ($p=0.014$); compliance and distance travelled ($p=0.005$); compliance and family support ($p=0.028$).

Conclusion: There is need for clinicians involved in the treatment of clubfoot to increase the knowledge of clubfoot and its treatment among the parents and caregivers. There also is need to improve the communication skills of clinicians offering treatment to children with clubfoot at the Talipes Clinics of the two hospitals. Finally, there is need to decentralize clubfoot treatment services away from referral hospitals to the people in the community through outreach programs.



DECLARATION

I declare that compliance of parents to the treatment regimen during the rehabilitation of children with clubfoot deformity in Mbarara Regional Referral Hospital and Mulago Hospital, Uganda is my own work and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.



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KAZIBWE HERMAN

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TABLE OF CONTENTS

Abstract	ii
Declaration	iv
Acknowledgements	iv
Table of contents	v
Appendices	xiii
List of tables	xiv
List of figures	xv
Abbreviations	xvi
Keywords	xvii

CHAPTER ONE

INTRODUCTION

1.1	Background	1
1.2	Statement of problem	3
1.3	Motivation for the study	3
1.4	Aim of the study	4
1.5	Specific objectives of the study	4
1.6	Significance of the study	4
1.7	Definition of terms	5


CHAPTER TWO

LITERATURE REVIEW

2.1	Introduction	8
2.2	Incidence of clubfoot	8



2.3	Causes of clubfoot	10
2.4	Patho-anatomy of clubfoot	10
2.5	Diagnosis of clubfoot	12
2.6	Management of clubfoot	12
2.6.1	Non-surgical interventions	13
2.6.2	Surgical interventions	18
2.7	Consequences of not adhering to non-surgical treatment	19
2.8	Compliance to treatment	23
2.9	Measurement of compliance	25
2.10	Factors influencing compliance	26
2.10.1	Socio-economic/financial factors	28
2.10.2	Travelling distance	29
2.10.3	Social/family support	30
2.10.4	Communication between clinician and parent	31
2.10.5	Waiting time	33
2.10.6	Negative attitudes of health care providers	34
2.10.7	Patient/Caregivers' knowledge about treatment	34
3.0	Summary	35
CHAPTER THREE		
METHODOLOGY		
3.1	Introduction	36
3.2	Research setting	36
3.3	Study design	38

3.4	Study population	38
3.4.1	Sample of convenience	40
3.4.2	Inclusion list	40
3.4.3	Exclusion list	40
3.5	Research instrument	40
3.5.1	Validity of the instrument	41
3.5.2	Reliability of the instrument	42
3.5.3	Translation of the questionnaire	43
3.6	Pilot study	43
3.7	Procedure of the study	44
3.8	Method of data analysis	46
3.9	Ethical considerations	46
3.10	Summary	47
		
CHAPTER FOUR		
RESULTS		48
4.1	Introduction	48
4.2	Socio-demographic findings	48
4.2.1	Age	49
4.2.2	Marital status	49
4.2.3	Employment	49
4.2.4	Education level of parents	49
4.3	Compliance	50
4.3.1	Age of treatment commencement	50

4.3.2	Referral of children to Talipes Clinics	51
4.3.3	Measurement of compliance	52
4.3.4	Compliance with the treatment	53
4.4	Parents' knowledge	54
4.4.1	Parent's knowledge of clubfoot and treatment	54
4.4.2	Parent's knowledge of the effect of non-compliance	56
4.4.3	Reasons for changing a plaster cast	56
4.4.4	Parents' role in treatment	56
4.4.4.1	Knowledge of parents of their current role in treatment	57
4.4.4.2	Knowledge of parents of their future role in treatment	58
4.5	Parents' views on communication between clinician and parent	58
4.6	Barriers to regular treatment attendance	59
4.6.1	Inadequate family support	59
4.6.1.1	Physical support	60
4.6.1.2	Financial support	60
4.6.2	Transport costs	61
4.6.3	Travelling distance	61
4.6.4	Waiting time	62
4.7	Association between compliance and parents' marital status, family support, travelling distance, cost of transport and waiting time, parents' knowledge about treatment and parents' experience of communication with the clinician	63
4.7.1	Association between compliance and marital status	64

4.7.2	Compliance and family support	64
4.7.2.1	Association between compliance and physical support	64
4.7.2.2	Association between compliance and financial support	64
4.7.3	Compliance and travelling distance	64
4.7.3.1	Association between compliance and travelling distance	64
4.7.4	Association between compliance and transport costs	64
4.7.5	Association between compliance and waiting time	64
4.7.6	Parents' knowledge about clubfoot and treatment	65
4.7.6.1	Association between compliance and parents' knowledge about clubfoot and treatment	65
4.7.7	Compliance and parents' experience of communication with the clinician	65
4.7.7.1	Association between compliance and parents' experience of communication with the clinician	65
4.8	Summary	66
CHAPTER FIVE		
DISCUSSION		
5.1	Introduction	67
5.2	Study sample	67
5.3	Commencement of treatment	69
5.4	Compliance of parents to the treatment regimen	69
5.5	Parents' knowledge of the importance of treatment	71
5.6	Barriers to compliance	73

5.6.1	Parents' experience of communication with the clinician	74
5.6.2	Travelling distance	77
5.6.3	Transport costs	78
5.6.4	Waiting time	79
5.6.5	Family support	80
5.7	Summary	80

CHAPTER SIX

SUMMARY, CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

6.1	Summary	82
6.2	Conclusion	83
6.3	Recommendations	83
6.4	Limitations of the study.	86



REFERENCES:		90
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APPENDICES

- APPENDIX 1 Questionnaire in English
- APPENDIX 2 Translated questionnaire in Luganda
- APPENDIX 3 Translated questionnaire in Lunyankole
- APPENDIX 4 Permission letter to conduct pilot study at OURS Centre.
- APPENDIX 5 Permission letter to conduct study at Mbarara Hospital
- APPENDIX 6 Permission letter to conduct study at Mulago Hospital



LIST OF TABLES

4.1	Marital status of parents	49
4.2	Age of child when treatment was started	51
4.3	Referral of children to the clinic	52
4.4	Parents' knowledge of clubfoot and importance of treatment	55
4.5	Reasons for changing a plaster	57
4.6	Parents' knowledge of their future role in treatment	58
4.7	Parents' experience of communication with the clinician	59
4.8	Source of financial support for parents	60
4.9	Distance parents travelled	61
4.10	Waiting time at the Talipes Clinics	62



LIST OF FIGURES

3.1	Map of Uganda	37
4.1	Parent's education levels	50
4.2	Point in regimen of interview	55
4.3	Compliant and non-compliant parents	54



ABBREVIATIONS

AIDS Acquired Immune-Deficiency Syndrome

HIV Human Immune-deficiency Virus

MOH Ministry Of Health

OCO Orthopaedic clinical officer

SPSS Statistical Package for Social Science

USA United States of America

WHO World Health Organization



KEY WORDS

Compliance

Parents

Children

Congenital

Clubfoot

Rehabilitation

Plaster-casting

Knowledge

Barriers

Uganda



CHAPTER ONE

INTRODUCTION

1.1 Background

Disability has emerged as a major public health problem worldwide. Physical disabilities are common in nations with disparate levels of socioeconomic development (White Paper on an Integrated, National Disability Strategy, 1997). However, the burden of childhood disability as a public health problem in developing countries remains relatively unrecognized (Shawky, Abalkhail and Soliman, 2002).

Clubfoot presents early in neonatal life and if not treated becomes more disabling with age. Neglected or inadequately corrected clubfoot can have a dramatic effect on the quality of life of the child. It causes physical impairments that result in decreased ambulation and inability to perform basic tasks such as carrying water, collecting food and going to school. This leads to dependency for activities of daily living with significant economic impact on the family. In addition, the structural differences in children with clubfoot are associated with social stigma, which has a psychological effect on the child.

Rehabilitation services are internationally recognized as one of the key components of health care (WHO, 1995). The aim of rehabilitation in clubfoot is to correct the impairment so as to improve function, prevent activity limitations, prevent participation restrictions, prevent social and educational disadvantage, and to improve the quality of life of the child (Pal, Chaundhury, Sengupta and Das, 2002). However, according to Bhatia and Joseph (2001), the emphasis of health care in many developing countries is directed primarily to curative and preventive aspects of disease, with rehabilitation getting less attention. Scarcity of resources and inappropriate distribution of health care professionals between rural and urban regions add to problems of rehabilitation in

developing countries. This has resulted in many patients in poor rural settings going without treatment or having to travel long journeys to urban areas for treatment. For example, it has been shown that only 10% of children with clubfoot in East Africa are able to access treatment from a specialist owing to inadequate awareness, poor communication, travel expenses and increased parental responsibilities of care in the family (Scott and Evans, 1997). Currently, only 2% out of over one million people with disabilities in Uganda receive rehabilitation services (Ministry of Health (MOH), 2003a). This includes children with clubfoot.

Physiotherapists are essential members of the rehabilitation team in clubfoot treatment both in developed and developing countries (Shack and Eastwood, 2006). Physiotherapists not only offer treatment to children with clubfoot, but also educate parents/caregivers about the diagnosis, the treatment process and the expected outcome (Ireland, 2003). However, just as early diagnosis, proper assessment of the functional capacity and needs of the child and providing early intervention are important, active parental involvement in the treatment process through consistent adherence to treatment requirements is also important for achieving good treatment outcomes (Shack and Eastwood, 2006).

Patient compliance with treatment procedures is important for the therapeutic regimen to be effective. Without compliance, the therapeutic goals cannot be achieved, resulting in poor patient outcomes (Cameroon, 1996). Research on adherence to paediatric treatment regimes has received attention in recent years as sub optimal adherence to medical and other therapeutic regimens can have personal, social and clinical implications for the child as an adult (De Civita and Dobkins, 2005). Lack of information regarding reasons for adherence to the regimen makes it difficult for health providers and health planners to determine the impact of treatments on health status or weigh the cost/benefit ratio for prescribing costly treatments to the patients (Modi, Lim, Geller, Wagner, Quittner, 2006). Therefore, it is important to understand how parents/caregivers manage their children's treatment and the potential barriers these parents encounter during the utilization of clubfoot treatment services. It is important to determine the compliance of patients to

clubfoot correction treatment in order to identify and target factors that may positively or negatively influence parents/caregivers attending the clinic.

1.2 Statement of the problem

Clinical records of 2004 at the Talipes Clinics at Mbarara Regional Referral Hospital and Mulago Hospital in Uganda indicate that parents/caregivers of children with clubfoot often stop attending or miss one or two treatment sessions during the phase of plaster casting. It was found that four patients out of the 24 patients seen in a period of three weeks at Mbarara Regional Referral Hospital miss one or two treatment sessions. These parents/caregivers come from different socio-economic and cultural backgrounds, have diverse educational levels, and often travel long distances to the clinics. It is therefore important to find out what factors influence the regular attendance of these parents/caregivers at the clinic. Currently, there is no published information in Uganda on the compliance of parents/caregivers to attending the clinic during the plaster casting phase.

1.3 Motivation for the study

The motivation for this study arose from the researcher's own professional experience with children that were undergoing clubfoot treatment at the Talipes Clinic at Mbarara Regional Referral Hospital. Few of the parents/caregivers of children seen at the clinics were not compliant with the treatment appointments given to them. This not only affected the effectiveness of the treatments but also resulted in wasting of the hospital resources for instance plaster of Paris bandages (each plaster of Paris bandage costs \$ 2.92 and an infant with bilateral clubfoot may require four or five POP bandages for plastering which will cost between \$11.68-14.6) and, prolonged the duration of the treatment regimen. The study limited its investigation into the plaster-casting phase of treatment because this is the treatment phase where regular visit by the parent/caregiver to the Talipes clinic on a weekly basis is a necessity for achieving good correction of the deformity.

1.4 Aim of the study

The aim of the study was to investigate barriers to treatment attendance parents of children with clubfoot encounter in complying with clubfoot treatment during the plaster casting stage at Mbarara Regional Referral Hospital and Mulago Hospital.

The aim of the study was to investigate barriers to treatment attendance parents/caregivers of children with clubfoot encounter in complying with clubfoot treatment during the plaster casting phase.

1.5 Specific objectives of the study

In order to achieve the aim of the study, the following objectives were identified:

- i. To identify parents' knowledge of clubfoot and its treatment
- ii. To investigate parents' roles during the plaster-casting stage of clubfoot treatment.
- iii. To identify the difficulties parents experience in attending all treatment appointments.
- iv. To identify associations between compliance to treatment and parent's knowledge about clubfoot, parents' experience of communication with the clinician, and the difficulties parents experience in attending all treatment appointments.

1.6 Significance of the study

The aim of physiotherapy is to prevent the activity limitation and participation restriction experienced by children with inadequately treated or neglected clubfoot, and to improve the quality of life of children with clubfoot. A major implication of the increase in the number of children growing with inadequately or uncorrected clubfoot is the probability of an increase in the prevalence of physical disabilities in the community. This not only results in a greater number of people requiring a wider range of health services including health promotion and rehabilitation but also results in a large number of these children failing to acquire the basic needs of life such as education and, socialization and, leads to poor quality of life. The results of the study may assist in increasing the awareness of the

benefits of complying with clubfoot treatment regimen among parents/caregivers. It may also be used in planning and implementation of awareness programs about clubfoot and its treatment in Mbarara and Kampala. Similarly, the results of the study may be used in the School of Physiotherapy and School of Orthopaedic Clinical Officers at Mulago Hospital to illuminate areas that may require more attention in the field of paediatrics that may be important for the students before completing their clinical practice course. Lastly the results may be valuable to researchers interested in conducting further studies, on barriers to regular treatment attendance, encountered by parents/caregivers so as to improve compliance of patients to clubfoot treatment regimen at the Talipes Clinics in Uganda.

1.7 Definition of terms

In the context of this particular study, namely, compliance of parents/caregivers of children with clubfoot to the treatment regime during the plaster casting phase in Mbarara Regional Referral Hospital and Mulago Hospital in Uganda, the terms used are defined below

Compliance

Compliance with clubfoot treatment, as used in this study, is defined as the ability of the parent to bring the child consistently every week for treatment (manipulations and plaster cast changes) at the Talipes Clinic for 5 weeks (Ponseti, 2003).

The researcher has opted to use compliance and adherence throughout this document. Adherence to treatment is defined as following treatment instructions, accepting restrictions and keeping given appointments (Gail, Carmel, Lubertzky, Vered and Heiman, 2001).

Parent and caregiver

In this study, the term ‘parent’ refers to the child’s biological parent whereas ‘caregiver’ refers to other carers such as grandparents, and other relatives or supporters. These two terms are utilized because the biological parents may not necessarily be the prime

caregiver of the child or the person who brings the child for treatment at the Talipes Clinic.

Congenital

Congenital refers to a condition that is recognized at birth or that is believed to have been present since birth (Oxford Concise Medical Dictionary, 2000).

Clubfoot

Clubfoot is a congenital deformity of the lower limb characterized by smaller calf muscles and adductus of the forefoot, cavus (increased longitudinal arch), varus of the heel (heel turned in) and equinus of the foot (foot in plantar flexion) (Morcuende, 2006).

Rehabilitation

This refers to all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualization. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation (WHO, 2002).

Plaster cast

This refers to a protective covering made of calcium sulphate white powder mixed with water, which sets hard when it dries up. It is commonly used to immobilize a particular part of the body for a specific period of time for example a fracture to allow healing to take place (Merriam-Webster Medical Dictionary, 2006).

Chapter outline

This mini thesis consists of six chapters. Chapter one provides an introduction, aim and objectives plus motivation of the study. Chapter two is the study of the literature for this study where literature on incidence of clubfoot, treatment methods and barriers to treatment attendance shall be highlighted. Chapter three will describe the methodology this study used, while in chapter four, the results of this study shall be presented. Chapter

five shall present a discussion of the results. Finally, in chapter six the conclusion, limitations of this study and the recommendations, based on the results, are presented. The next chapter presents the relevant literature that was reviewed.



CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

In this chapter, the literature review gives an overview of the incidence of clubfoot and the suggested causes. In addition, the literature explains the pathophysiology of clubfoot and its treatment and the consequences of not adhering to the rehabilitation treatment regimen. The literature, which defines compliance and its relevance to treatment, is reviewed. This is followed by a review of literature on the barriers to compliance that parents attending for treatment encounter.

2.2 Incidence of clubfoot

Studies worldwide indicate variations in the incidence of clubfoot. The variations appear to be due to differences in race, population studied and geographical location of the study (Roye and Roye, 2002). Studies conducted in America and the United Kingdom estimate the incidence of clubfoot in developed countries to be 1 per 1000 births, with males more affected than females in a ratio of 2:1 (Moorth, Hashmi, Langois, Canfield, Waller and Hecht 2005). One study done in the United States of America, by Morcuende, Doran, Dietz and Ponseti (2004) indicate that 2224 children are born annually with clubfoot and approximate this figure to an incidence of 0.6 cases per 1000 live births. In a similar study, Barker, Chesney, Miedzybrodzka, and Maffulli (2003) estimate the incidence of clubfoot to vary from 0.64 to 6.8 per 1000 live births globally, and report an incidence of 2.57 per 1000 births in the United States of America. However, findings of Pandey and Pandey (2001) indicate an incidence of 2 to 3 per 1000 births in developed countries. Studies done in other countries such as Japan indicates an incidence rate of approximately 0.5 per 1000 live births and, an incidence of 7 per 1000 births is reported in natives of the South Pacific islands (Ballantyne and Macnicol, 2002). Similar findings by Chapman, Scott, Port and Nicol (2000) identified an incidence of 0.5 per 1000 birth

among the Chinese population and, that of 6 to 7 per 1000 birth among the Maori population in New Zealand.

Studies have analysed the differences in the incidence of clubfoot for different racial groups. Carey, Bower, Mylvaganam and Rouse (2003) identified an incidence of 1.25 per 1000 births in Western Australia, and an incidence of 3.49 per 1000 births among the aborigines, with males affected almost four times more often than females. In Hawaii, a study by Barker et al (2003) found an incidence of 6.8 per 1000 births among the natives and, they suggested that East and Central Africa together with Polynesia have the highest incidence of clubfoot of 8 per 1000 births.

Information on the incidence and prevalence of clubfoot in Africa is limited except in a few countries including South Africa, Malawi, Uganda and Zimbabwe where studies on clubfoot have been conducted. The incidence of clubfoot among black South African children is reported to be 3.5/1000 births (Ballantyne and Macnicol, 2002). In Malawi, the incidence of clubfoot is estimated to be twice that in Western Europe (approximately 2 to 3 per 1000 births) (Tindall, Steinlechner, Lavy, Mannion and Mkandawire, 2005). In Zimbabwe, a study by Madzivire, Useh, Mashegede and Siziya (2002) found the incidence of clubfoot to be 0.9 per 1000 births.

Although it is estimated that 85% of the world's disabled children under 15 years of age live in developing countries, not much is known about the disabling conditions such as clubfoot in these countries (Shawky, Abakhail and Soliman, 2002).

Uganda like many other developing countries has no available data on the incidence and prevalence of clubfoot. Konde-Lule, Neema, Gitta and McElroy (2005) estimate the incidence of clubfoot in Uganda to be 2 to 4 per 1000 births, and suggest there are 10000 children living with the condition. However, they suggest that the number of children born with clubfoot and those living with the impairment could be higher than the

estimated figures as many children with clubfoot are not diagnosed or do not receive treatment.

2.3 Causes of clubfoot

Studies on clubfoot (Chapman et al, 2000; Dietz, 2002; Roye and Roye, 2002) suggest that the exact cause of clubfoot is not known. Epidemiological studies done on clubfoot have identified several factors that could be linked to the cause of this condition. Baker et al (2003) classify the possible causes of clubfoot into two categories. These include intrinsic and extrinsic influences on the developing foetus. The intrinsic causes include chromosomal abnormality and sex linked genes. The extrinsic causes include the intrauterine environment. Factors that are considered to be linked to the intrauterine environment include increased uterine pressure, abnormal foetal positioning, constriction bands, temperature changes, unstretched uterus and placental insufficiency.

Likewise, the findings of Chapman et al (2000) indicate that a single dominant gene is responsible for the development of clubfoot. They suggest that the likelihood of the affected subjects carrying a copy of the gene predisposing to clubfoot is sufficiently high and concluded that any family with multiple affected members is almost certain to be carrying a copy of this gene. Other proposed causes of this condition of which evidence is limited include chromosome defects, vascular and neuromuscular abnormalities, and viral aetiologies.

Clubfoot also occurs or exists with other conditions such as spina bifida and arthrogryposis and, it is reported that this type of clubfoot is expected to be more difficult to treat (Faules and Luther, 2005).

2.4 Patho-anatomy of clubfoot

Anatomical studies have been done to fully understand the complexities of the deformities of clubfoot. Nevertheless clear understanding of these deformities and the

proper interrelations between the tarsal bones remains controversial (Pandey and Pandey 2002). Clubfoot is characterized by four deformities of the foot. These include rigid equinus of the foot (foot is in plantar flexion), cavus of the mid foot (increased longitudinal arch of foot), varus of the hind foot (heel turned in) and adductus of the forefoot at the midtarsal joints (fore foot in adduction) (Mocuende, 2006).



Structure of clubfoot Source: <http://images.google.co.za> (8/11/2006)

According to Roye and Roye (2002), the talus and calcaneus in a clubfoot are medially rotated, and plantar flexed. The plantar flexion is said to cause a larger part of the articular surface of the talus to lie outside the mortise of the navicular bone. The hyaline cartilage in this joint develops abnormally because it is not articulated with the rest of the joint. In addition, stunted growth occurs on the anterior surface of the talus and normal growth occurs on the medial side, which articulates with the subluxed navicular bone. This preference in growth on the talar head is said to pull the calcaneus into abduction. Further more, the spring and deltoid ligaments together with the posterior tibialis tendon undergo fibrotic shortening that causes the foot to appear inverted and adducted.

Studies by Ponseti (1997) on anatomic dissections of clubfeet revealed that the calcaneus, navicular and cuboid bones are rotated medially in relation to the talus and are firmly held in adduction and inversion by very tight ligaments and tendons. Similarly, the navicular bone is severely displaced, close to medial malleolus and articulates with the medial surface of the head of the talus. In addition, the muscles and tendons of gastrocnemius, tibialis posterior and toe flexors are shortened and atrophied whereas the ligaments of the posterior and medial aspect of the ankle and tarsal joints are very thick, taut and shortened, restraining the foot in equinus. Ponseti came to the conclusion that the shortening of the talocalcaneal ligament and joint capsules on the medial side of the foot are responsible for the adduction and varus deformities together with the curved structure of the clubfoot.

2.5 Diagnosis of clubfoot

According to Bussing, Zima, Gary and Garvan (2003), diagnosis of the problem usually serves as the first step of the treatment process, which may be followed by steps to obtain an assessment, diagnosis and treatment. Research has also shown that early recognition of disease especially in children determines the treatment responses or interventions that can be employed (Salako, Brieger, Afolabi, Umeh, Agoma and Asa, 2001). It is said that due to the structural nature of clubfoot, the deformity is easily recognized from birth by either traditional birth attendants in villages or professional doctors and midwives in public and private health facilities attending to mothers during delivery of these children (Konde-Lule et al, 2005).

On the other hand, it's the parent's instinct to investigate the health and status of a newborn. Clubfoot that becomes so evident after birth can easily be identified by parents especially the mother during her routine observation and assessment of the infant. However, it is suggested that lack of awareness by the parents/ caregivers about the disease and not knowing where to go for treatment, causes delays in early seeking of treatment for the patient (Seedat, Stein and Wilson, 2002). Similarly, Konde-Lule et al (2005) assert that owing largely to lack of awareness of the condition, illiteracy and geographical inaccessibility to health facilities with services for treating clubfoot, many parents in Uganda do not seek-out treatment early. Rehabilitation care is still a new approach in Uganda and, due to a lack of awareness about the availability of rehabilitation services and the rehabilitation potential, parents, especially those in rural areas living far away from health facilities, seek alternative treatment or sometimes do nothing for the impairment of the child (Konde-Lule et al, 2005).

2.6 Management of clubfoot

Several methods have been used to correct clubfoot with the aims of improving function, preventing activity limitations and participation restrictions together with improving the physical and social functioning of the child. In addition, the purpose of treatment is to achieve a functional, pain free, plantigrade foot, with good mobility and with no need for the child to wear modified shoes (Morcuende, Dolan, Dietz and Ponseti, 2004; Dobbs,

Rudzki, Purcell, Walton, Porter and Gurnett, 2004). It is suggested that correction of the deformity not only reduces stress among parents, caregivers and family members, but also eliminates stigma associated with clubfoot impairment. As described in section 2.4, clubfoot encompasses a spectrum of foot deformities that often result in long term impairments and, present considerable challenges to clinicians and orthopaedic surgeons (Herd, Macnicol and Abbound, 2004). Several treatment interventions are used to correct clubfoot and these have been categorised into non-surgical and surgical interventions (Colburn and Williams, 2003; Roye and Roye, 2002).

2.6.1 Non-surgical interventions

The initial treatment options of clubfoot in the past were variations of manipulation and splinting and surgical interventions but with none of them universally accepted as the initial treatment intervention (Roye and Roye, 2002). However, following increased studies on the patho-anatomy of clubfoot, there is universal agreement that the initial treatment of congenital clubfoot should be nonsurgical regardless of the severity of the deformity (Dobbs et al, 2004; Morcuende, Dolan, Dietz, and Ponseti, 2004; Colburn and Williams, 2003). Non-surgical interventions for treating clubfoot involve correcting the deformity so as to achieve a functional foot. According to Pandey and Pandey (2003) non-surgical methods have evolved from ancient times when surgeons recommended correction of the deformity by use of massage in infants, splintage in early childhood and adaptive footwear in adults, to use the latter day use of manipulations and plaster casts. Similarly, methods of maintaining correction of the foot have also passed through a variety of stages including using egg yolk immersed rag wrapping of the foot, the use of adhesive strappings, plaster of Paris, wooden and other material splints and various types of surgical boots (Pandey and Pandey, 2003). However, through research and the advancement in biomedical technology, a number of methods proven to be effective have been developed to correct the condition. The most frequently used non-surgical treatment methods that are documented in literature include: the French physiotherapy method (Richards, Johnston and Wilson, 2005); the Kites method (Roye and Roye, 2002; Noon and Richards, 2003); and the Ponseti method (Colburn and Williams, 2003; Dobbs et al 2004; Judd, 2004; Frick, 2005; Mocuende et al 2005).

Whereas it is reported that casting and splinting are the main techniques of nonsurgical intervention in North America, physiotherapy and continuous passive motion without the use of immobilisation using plaster castings have been used in Europe (Roye and Roye, 2002; Dobbs et al 2004). The French physiotherapy method involves daily stretching of shortened soft tissues of the newborn's clubfoot, cutaneous stimulation of the weakened peroneal muscles of the foot using light and gentle strokings, passive mobilisation of the foot joints followed by temporary immobilization of the foot with elastic and non elastic adhesive taping for 20 months (Richards, Johnston and Wilson (2005). This lengthy treatment requires good cooperation from the parent to bring the child for daily treatment sessions in addition to performing stretching, passive mobilisation exercises and strapping of the foot everyday at home for the required treatment time if good treatment results are to be achieved (Fauks and Luther, 2005).

However, it is suggested that this physiotherapy method may not be effective in some patients especially older infants and, its treatment duration is criticised for being long (Bensahel, Guillaume, Czukonyi, and Desgrippes, 1990). However, despite its shortcomings, the French physiotherapy method has been shown to be effective in correcting clubfoot in newborns. Although good treatment outcomes are reported with the French physiotherapy method in Europe, there is no literature about its use in developing countries including in Africa.

The Kite method has been the method of choice for correcting clubfoot in many countries in Africa (Roye and Roye, 2002). The Kite method involves applying a three-point pressure to the foot medially, and everting the heel as the foot is abducted, followed by application of a short plaster of Paris cast from the toes to below the knee. The cast is changed every week for the first 6 weeks then every 2 weeks until the age of four to six months. The plaster cast is changed to allow the clinician to inspect the foot, to provide mobilization exercises to the foot and to stretch the foot further in the correction position. In addition, changing plasters allows increase in the size of the foot and to maintain

cleanliness of the foot. Treatment requires an average of 20 months in casts followed by use of a brace for a lengthy period of time (Noonan and Richards, 2003).

However, although Kite achieved successful results, this method has met a lot of criticism from many researchers. It is suggested that only 15% of clubfoot responds satisfactory with the Kite method and the remainder require surgery to correct them (Roye and Roye, 2002). It is argued that Kite used incorrect manipulations to correct the foot and, the overall length of treatment, requiring the child to undergo three years of plaster cast treatment is too long (Dobbs, Morcuende, Gurnett, and Ponseti, 2000). The requirement for parents to undergo lengthy period of attending treatment sessions is suggested to be one of the reasons why Kite's method registered less optimal correction of the deformity due to treatment defaulting.

According to Norgrove (1999), Kite's method was widely used in Uganda before the introduction of the Ponseti method in 1999. Norgrove argues that the use of Kite's methods led to unsatisfactory treatment results. Ponseti (1997) asserts that scanty literature is available on non-surgical techniques of treating clubfoot and almost none is available on their outcomes in developing countries including Africa. Similarly, Segev, Keret, Lokiec, Yavor, Wientroub et al (2005) points out that while details of various surgical procedures used in the treatment of clubfoot are easy to find, the manipulative techniques and their results are rarely described.

The plaster casting technique has undergone several changes in past in an attempt to achieve good correction of clubfoot in infants within the shortest time possible. Ponseti modified Kite's casting technique by using external rotation of the foot around the talus to correct adduction; used a long cast from toes up to the mid thigh; reduced the equinus by use of an Achilles tenotomy; and made use of foot abduction braces to maintain abduction of the corrected foot (Roye and Roye 2002).

The Ponseti method was introduced in Uganda by Pirani in 1999, who had used it in Canada with good treatment outcomes. Pirani, together with Norgrove and, in

collaboration with the Disability Section of the Ministry of Health, the Department of Orthopaedics Makerere University and the Child's Orthopaedic Rehabilitation project, established a Rotary funded Ponseti treatment program for clubfoot that was named the Uganda Clubfoot Project. This project trained both local surgeons and other medical care professionals including orthopaedic clinical officers and physiotherapists in using the Ponseti technique and has increased public awareness about clubfoot and its treatment (Konde-Lule et al 2005). Orthopaedic clinical officers are paramedic practitioners who receive a 3-year diploma in orthopaedics. They receive basic training in medicine, orthopaedics and surgery from the School of Clinical Orthopaedic Officers from Mulago Paramedic Training institutions, after leaving advanced secondary school.

At the time of this study, all clinicians offering treatment to children with clubfoot at the Talipes Clinics of the two hospitals had undergone training in the Ponseti method. Treatment of clubfoot using the Ponseti method in Uganda is divided into two phases. The treatment phase, during which the deformity is corrected, includes the plaster casting and tenotomy phase and, the maintenance phase in which a foot abduction brace or orthosis is used to preserve the correction achieved and, to prevent recurrence of the deformity. The treatment phase involves gradual correction of the deformed foot, through stretching shortened structures, followed by plaster casting to maintain the correction that is achieved. This procedure is done weekly for five to six weeks (Judd, 2004; Morcuende et al 2004; Frick, 2005; Scher, 2005,).

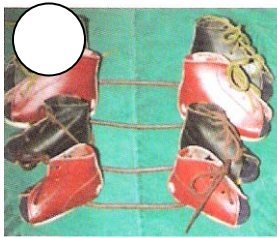


Children with plaster casts Source: <http://images.google.co.za> (8/11/2006)

At the end of six weeks, children with the corrected foot undergo a minor surgical procedure (tenotomy) to release the tight Achilles tendon, which is performed under local

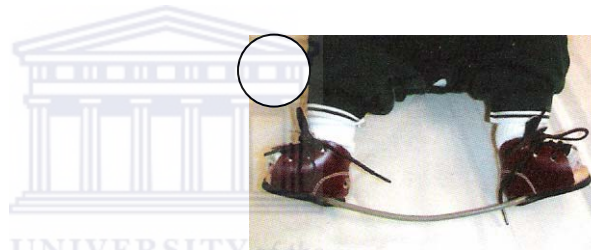
anaesthetic to correct the equinus and allow dorsiflexion of the foot (Dobbs et al 2004; Mocuende et al, 2005; Segev et al, 2005). A plaster cast is applied and worn for three weeks followed by fitting the baby with foot-abduction braces which are worn for up to 2 years to maintain the corrected position. The braces maintain the achieved correction by keeping the soft tissues stretched to prevent re-occurrence. According to Ponseti (1997), the baby is required to wear the braces for 23 out of 24 hours for three months, and for two years at night and nap times only.

It is suggested that the Ponseti method can be successful in correcting clubfoot when applied properly, and if there is consistent adherence to the treatment regimen in the two phases of treatment, although incomplete or defective correction may be common (Ponseti, 1997).



Foot abduction braces

Source: (Ponseti, 2003:24)



Child fitted with foot abduction braces

Source: (Ponseti, 2003:16)

However, failures with the Ponseti method have been reported in a few studies (Dobbs et al, 2004). Some attribute this to defaulting on treatment appointments; because children present late for treatment (Göskan, Bursali, Bilgili, Sivacioghi and Ayanoglu, 2006); and inconsistent use of foot abduction braces in the maintenance phase, as cooperation with nightly bracing for 2 years is considered difficult in some populations (Roye and Roye 2002).

Although generally considered safer than surgery, manipulations and serial casting have been reported to have complications which include: pressure sores; fractures if excessive pressure is used during cast application; rocker-bottom deformity that occurs if an

attempt is made to forcefully correct the equinus deformity or dorsiflexing the foot before correcting the adduction and varus components; increased cavus deformity; lateral rotation of the ankle; and increased stiffness of the foot joints (Ponseti, 1997; Royle and Royle, 2002; Colburn and Williams, 2003). For example, in Turkey, Göskan et al (2006) found that out of 92 patients that were treated with clubfoot, nine patients did not comply with the plaster casting regimen due to development of pressure sores, oedema and skin problems which interfered with the treatment. In addition, the researchers registered a relapse rate of 3% in the cases that were compliant with the plaster casting regimen and use of the foot abduction brace.

It is further argued that forced stretching of muscles followed by immobilisation using plaster casts elicits a defensive reaction in the stretched muscles resulting in co contraction of the stretched muscles which increases the degree of the deformity (Bensahel et al, 1990). In addition, it is suggested that forcible manipulations and splintage with plaster casts may compress and deform the cartilaginous tarsal bones, alter the congruity of joints and cause damage to articular surfaces of the foot joints (Macnicol, 2003). This confirms earlier findings by Göskan et al (2006), which indicate that inappropriate manipulations and castings used in various conservative treatments cause incomplete correction and in some cases damage the foot skeleton. It is suggested that muscle relaxation and lengthening should be the goal of treatment rather than elongation of tendons and ligaments (Macnicol, 2003).

2.6.2 Surgical interventions

Studies by Khan and Chinoy (2006), Hogue, Uddin and Sultan (2001), and Sureh, Ahmed, Sharma (2003) have shown that surgical correction is the only option to attain a functional foot in patients who fail to respond to non-surgical interventions, those who present late for treatment and those that received inadequate treatment or did not complete the plaster cast treatment. It is argued that whereas in developed countries non-surgical treatment may be the first choice due to early recognition and prompt treatment, in developing countries patients can present untreated months or even years after birth

rendering use of non-surgical interventions ineffective (Khan and Chinoy, 2006; Hogue, Uddin and Sultan, 2001).

The aim of surgical intervention is to restore as normal a structure and function of the foot as possible (Richard et al, 2002). However, the extent of surgery required varies according to the presentation of the patient (Ballantyne and Macnicol, 2002). There are many surgical methods of correcting clubfoot, however, two are commonly used. These are firstly, the posterior release and, secondly, the posterolateral and posteromedial releases (Hogue et al, 2001). Conversely, tendon transfers of more active muscle groups may be done to balance the muscular forces acting on the foot (Macnicol, 2003). However, regarding surgical correction of clubfoot, Ballantyne and Macnicol (2002) points out that under-correction of clubfoot leads to recurrent deformity whereas over release of tight structures may lead to a valgus heel and a stiff foot.

According to Ponseti (1997) and Uglow and Clarke (2000), surgical interventions are associated with other problems such as wound infections, fibrosis, severe scar formation, stiffness of joints, weakness of the plantar flexors of the ankle, pain in the corrected foot, or relapses and the need of additional surgery. In addition, it is argued that in infants of less than three to six months of age, foot size makes surgery technically demanding, as identification of anatomical structures becomes difficult (Roye and Roye, 2002). Conversely, surgery at this age leads to increased scar formation that compromises the function of the tissues. It is suggested that delaying surgery allows for prolonged conservative management, which may prevent the progression of the deformity and thus reduce the extent of surgical release required (Ballantyne and Macnicol, 2002).

2.7 Consequences of not adhering to non-surgical treatment

Poor adherence to treatment among patients and their caregivers in form of missing appointments is said to be a major dilemma facing clinicians in the health care delivery today (McEvoy, Nydegger and Williams, 2003).

McEvoy, Nydegger and Williams (2003), assert that this is caused by the patient or caregiver not understanding the nature of the condition and its treatment or having unrealistic expectations of treatment. It is alleged that therapeutic efficacy in any treatment intervention is to a large extent determined by the adherence of patients to treatment requirements, which also applies to clubfoot (Lewis and Fink, 2001). In contrast it is said that without strict adherence to the treatment requirements, the effectiveness of any therapeutic intervention geared at improving the condition of the patient is severely undermined. Studies on adherence to medical care have shown that poor adherence of patients to treatment regimes leads to reduced clinical benefit since the primary objective of treatment is not met. It increases secondary complications and health care costs and reduces quality of life of the patient (Proctor, Theodore and Gatchel, 2005; Retinster and Neuprez, 2006). It is further indicated that a patient whose parents do not comply with the treatment protocol of clubfoot treatment in the two phases stand more chances of developing a relapse of the deformity than one whose parents comply (Dobbs et al, 2004).

The results of studies by Proctor et al, 2005; Retinster and Neuprez, 2005; and Dobbs et al, 2005 indicate that adherence to clubfoot treatment protocol is vital for achieving successful treatment results or outcomes. For example, Segev et al (2005) report that in Israel, strict adherence of parents to the treatment and maintenance phases enabled them to correct more than 90% of congenital clubfoot cases. Vauth, Loschmann, Rusch and Corrigan (2004) supports this finding and indicate that although compliance in itself does not guarantee complete correction of clubfoot, the gradual improvement in the structure and function associated with compliance may be one of the most important aspects of treatment outcome.

Pesata, Pallija and Webb (1999) further indicate that missed appointments not only disrupt the child's continuity of care, but also disrupt the relationship between the caregiver and the health care provider leading to frustration on the part of the health care provider. They further assert that this frustration may alter communication with the family and decrease empathy for the family in future interactions. Further more, they

emphasize that parents or caregivers who miss appointments deprive themselves of professional services, disrupt caregiver-provider relationships, reduce opportunity for other patients to receive timely care by taking appointments away from those who may need it, and indirectly contribute to rising health care costs.

Poor adherence to the initial plaster casting regimen of clubfoot treatment leads to poor treatment results, relapses and development of more rigid foot deformities that are difficult to correct (Sureh, Ahmed and Sharma, 2003). In a study on neglected clubfoot in India, Sureh, Ahmed and Sharma found that many patients with clubfoot, especially those from rural areas, presented with neglected or inadequately treated clubfoot that required complex surgical procedures to correct them. This was attributed to ignorance of parents about the benefits of adhering to the treatment regimen and barriers that prevent parents from following the treatment requirements.

In Africa, only one study on adherence was found. This study was conducted by Scott and Evans (1997) in Tanzania on compliance of parents to the casting regimen. In this study at St Francis Hospital, Kwa Mkono, Handeni District, Tanga region in Tanzania, Scott and Evans found that out of the 26 children that were recruited in the study between 1990 to 1993, and

despite parents appearing to understand the reasons behind treatment and, being shown improvement in their children's feet, only a minority of the children were brought on more than three occasions for treatment. It is further reported that no child was brought to the hospital over a sufficient period of time to either be discharged as cured or for surgery to be considered following failure of conservative care (Scott and Evans, 1997:23).

This indicates an enormous dilemma of adherence of patients/caregivers to treatment regimens in poor resource settings of developing countries especially in Africa. Non-compliance to treatment regimens does not only compromise on the effectiveness of interventions, but also facilitates development of more complications that may be difficult to correct, which can result in more disability (Roye and Roye, 2002).

If left untreated or given inappropriate treatment, a child with clubfoot will begin walking on the lateral border of the foot as he/she grows up, and later, the foot turns inward and eventually he/she walks on the dorsum of the foot. In addition, the child develops pain, stiffness in the joints of the foot, and abnormal gait patterns. Special footwear is required to accommodate the impairment which increases activity limitation (Mocuende, 2006).



Source: <http://images.google.co.za> (8/11/2006)



Source: (Konde-Lule et al, 2005:9)

Older children with poorly treated or neglected clubfoot

Similarly, children with clubfoot have difficulty in playing with their peers and going to school, and are frequently subject to mockery (Norgrove, 1999). This can be associated with long-term psychological difficulties which affect the quality of life of the child. The inability to maintain the foot in a plantgrade position and locomote without pain can alter the dynamics of social interactions and may influence the degree to which a child with clubfoot can successfully interact with the environment, increasing participation restrictions (Konde-Lule et al, 2005). Children with clubfoot especially girls, are less likely to get access to education, especially those from families with poor social economic backgrounds and, are less likely to become educated than boys with the same impairment. This is because in many cultures in Uganda, boys are given high priority in terms of provision of the basic needs and care than girls. In addition, girls with physical disabilities are considered a waste so that provision of education to these children is considered a waste of family resources.

2.8 Compliance to treatment regimen

The studies on compliance that are reported on were done on parents or caregivers. Only one study was found on the compliance of parents of children with clubfoot to treatment during the plaster casting stage. This was by Scott and Evans (1997). The few studies that have been done on compliance of parents to treatment of clubfoot were in the maintenance phase, the phase after plaster casting, on use of the foot abduction braces (Dobbs et al. 2004; Thacker, Scher, Sala, Van Bosse, Feldman et al. 2005).

According to Chappell and Williams (2002), compliance or adherence to treatment regimes is a difficult concept to define and measure. They assert that research into adherence has drawn on a number of social cognition models including health locus of control, the health belief model and Leventhal's self regulatory model but all have had minimal success in explaining adherence problems among parents/caregivers of children.

Definitions of compliance to treatment vary among different researchers and different disciplines. The terms compliance and adherence have been used interchangeably in some studies to indicate patient or caregiver's willingness to follow the required treatment program (Sewitch, Dobkin, Bernatsky, Baron, Starr, Cohen and Fitzharks, 2004). Buck, Jacoby, Baker and Chadwick (1997:87) state that some researchers believe that "any patient who fails to adhere on one occasion or more is non-compliant whereas others feel that only those who fail to comply more than occasionally say at least 25% of the time should be regarded as non-compliant". Nose and Barbui (2003) defines compliance as the extent to which a person's behaviour coincides with the treatment advice given, and non-compliance as the failure to enter a treatment program, premature termination of treatment and incomplete implementation of instructions from the clinician.

On the other hand, Nock and Ferrister (2005) differentiates between adherence and compliance. They describe adherence as a partnership between the clinician and the patient or caregiver. They suggest that adherence is an active, voluntary and collaborative involvement of the patient to produce a desired therapeutic result whereas compliance is obedience and acceptance, following the orders of the clinician. Cameron (1996)

describes compliance as the willingness of the patient/ caregiver, to follow treatment prescriptions, and a behaviour that is related to the actual carrying out of prescriptions. Cameron likewise alleges that compliance represents an underlying authoritarian tone on the side of the health care provider and a submissive image of patients or caregivers. Cameron indicates that other terms such as adherence and therapeutic alliance are often used in preference to compliance. He suggests that the three terms represent points along a social control continuum, where compliance is suggested to indicate coercion, adherence to designate conformity and therapeutic alliance to signify negotiation. However, it is suggested that the continuum varies in the degree to which the patient is active about the decisions being made about him/herself or inversely the degree to which others determine the patient's behaviour.

Similarly, Lutfey and Wisher (1999) describes compliance as the patient's willingness to obey the health care providers' instructions in conformity to treatment defined goals; and adherence as the ability of patients or caregivers to independently take more active and voluntary roles in pursuing goals for their treatment. Lutfey and Wisher suggest that adherence minimises the authoritative practitioner-submissive patient model of health care. Cork, Britton, Butler, Young, Murphy and Keotiane (2003) oppose the use of the term compliance in clinical fields as it symbolises submission of the patient or caregiver to the orders or conditions of the prescribing clinician or therapist. They instead recommend the adoption of the term concordance, which indicates cooperation between the patient or caregiver and the clinician to produce the best treatment outcome.

On the other hand, Leventhal, Riegel, Carlson and De Geest (2005) describe compliance as the patient or caregiver's free choice of behaviours from those recommended by the clinician. They argue that compliance is a contractual relationship between the clinician and patient or caregiver, to help the patient or caregiver to balance his/her personal life and the needs of the required treatment during the course of treatment.

Similarly, Gail, Carmel, Lubertzky, Vered and Heiman (2001) describes parental compliance to rehabilitation programs of children as the ability of the child's parents to

abide by the requirements of rehabilitation treatment, which includes following treatment instructions, accepting restrictions and keeping given appointments.

According to Penny (2005), failures in treatment or recurrences are in most cases as a result of non-compliance with the two phases of treatment. However, most of the available literature looks at compliance in the maintenance phase using bracing. Göskan et al (2006) indicated that 90% of the patients (n=92) in their study in Turkey complied with the initial plaster casting regimen but only 58% complied with the foot abduction bracing. They suggest that this low compliance rate is due to poor cooperation with the bracing protocol that is required to be done for a long time, an exercise that is seen to be difficult in many populations. In a study on clubfoot in Missouri USA, on factors predictive of outcome after the use of the Ponseti method, Dobbs et al (2004) registered a compliance rate of 60% among patients in the use of the foot abduction braces. Seventy-six percent of the patients whose parents had not complied with the treatment protocol of consistently using abduction braces, developed relapse of the deformity.

In summary, compliance is the willingness of the parent/caregiver to abide by the treatment prescriptions and requirements. This involves keeping treatment appointments given at the Talipes Clinic, attending regularly to treatments as required and, fulfilling treatment instructions.

2.9 The measurement of compliance

Barakat, Smith-Whitney and Ohere-Frempong (2002) assert that despite serious consequences of poor compliance to prescribed therapeutic regimens for children with physical and mental impairments, compliance or treatment adherence in this group of children has not been well studied. They argue that examination of treatment adherence in children is hindered by difficulty in developing standard, reliable and valid measures. Several procedures have been used in literature to assess adherence or compliance of patients in medical treatments and these include ratings made by health care providers, parents and child reports in interviews (Duff, 1999).

Leventhal, Reigel, Carlson and De Geest (2005) suggests that the best method of measuring compliance is by the direct method of observation but because this is rarely feasible, other indirect methods such as self report, collateral report, clinical outcomes, self monitoring, pill or medication counts, prescription refills or electronic event monitoring, biological indices and health status are usually used. It is argued that each of these methods has its strength and weakness. For instance it is indicated that use of health provider, parent and child reports in interviews tend to overestimate adherence, whereas use of objective measures such as number of times child attends treatment, self monitoring, pill counts, biological indices, electronic monitoring and health status do not account for the many skills and behaviours involved (Barakat et al, 2002). Rapoff (2006) suggests that over estimation of adherence in patient's and caregiver's reports is due to social desirability effects as patients and families may want to please the health provider by reporting that they are behaving in socially approved ways such as adhering to treatments.

On the other hand, Rapoff (2006) reports that patients or caregivers reports through interviews provide detailed information on adherence patterns and types of barriers encountered, which can be helpful in helping the patients and families improve their adherence by identifying circumstances and specific barriers that prevent them from being consistent in following the prescribed treatment (Rapoff, 2006). These findings suggest that compliance to therapeutic interventions is a complex behaviour that cannot be accurately measured with one particular method. This supports earlier findings by Buck, et al (1997) which indicate that just as the definition of compliance is problematic, so too is its measurement

2.10 Factors influencing compliance

Research in rehabilitation has shown that consistent attendance at treatment appointments plays a central role in both improving structure and function, is associated with good treatment outcomes, increased activity participation and improved quality of life of the patient. This section looks at the factors that might hinder parents/caregivers or act as

barriers to compliance with clubfoot treatment regimen. The literature reviewed in this section is categorised in subsections which include: socio-economic/financial factors; travelling distance; social/family support; communication between the clinician and the patient; waiting time at the Talipes Clinics; negative attitudes of health care providers; and patient/caregiver's knowledge about the condition.

According to Lerman, Gomez-Perez, and Rull (2004); Kyngäs (1999), patient/caregiver's behaviour during treatment is influenced by interactions within the family system, between the patient/caregiver and the health provider, and within the health care system and the external environment. Kerkorian, McKay and Bannon (2006), on the other hand suggests that the quality of experience obtained by the patient or caregiver during treatment influences treatment-seeking decisions and keeping treatment appointments. For example, it is said that positive assessments of the previous contact with a health care provider are associated with higher intentions to seek treatment in future whereas negative experiences and expectations they produce have the reverse effect (Deane, Wilson and Ciarrochi, 2000). However, Kazdin and Wassell (1999), describes these influences as barriers to attendance to the required treatment. They assert that families who perceive more barriers are likely to be less involved in and committed to treatment, and less likely to carry out treatment prescriptions than those who perceive fewer barriers. These findings suggest that compliance to therapeutic interventions can be influenced by many factors that can present as barriers to treatment attendance.

Research on barriers to treatment attendance has classified these influencing factors into different groupings. McCohachie, Huq, Munir, Komrunnabar, Akhter et al (2001) categorises these factors into: economic factors which include travel and treatment costs; physical factors which consist of travelling distance and accessibility of health facilities; psychological factors that include patient or caregiver's beliefs (both cultural and religious) and knowledge of patient about treatment. Similarly, Leventhal et al (2005) differentiates these factors into social-economic, health care setting and system related factors, condition related factors, treatment related factors and patient related factors. Likewise, Taylon, Dodd, McBurney and Graham (2004) categorise these factors into

environmental and personal factors. The environmental factors include family support, complexity of the treatment program, relationship between the patient and health provider, and support from the health care provider whereas the personal factors include the patient or caregiver's decision to participate and follow the prescribed treatment.

2.10.1 Socio-economic/ financial factors

Socio-economic factors have been shown to be a major hindrance to access to health care services in most resource-poor settings. Meremikwu, Ehiri, Nkanga, Udoh, Ikpatt and Alaje (2005), assert that despite the availability of effective treatment interventions and the high cure rate, the outcome of treatment in many parts of Africa remains sub-optimal due to poor socio-economic conditions and poor health seeking behaviours. Meremikwu et al document that in most poor countries where Burkitts Lymphoma is endemic, many affected families cannot afford the cost of basic laboratory diagnostic tests, causing this treatable condition to be a cause of considerable distress and early death in the affected children.

Sharkawy, Newton and Hartley (2006), in a study on attitudes and practices of families towards children with epilepsy in Kenya, found that poor socio-economic situations in families affected the parents' use of medical services for their sick children at health facilities. This led them to resort to the least costly services such as religious or traditional treatments. In a study in Ghana, on options of care seeking, Hill, Kendall, Aurthur, Kirkwood and Adjel (2003) found that financial access by the parents/caregivers was a major barrier to appropriate health care seeking for their sick children. Bodydell, Pong, Volpe, Tilleczek, Wilson et al (2006) document that accessing health care services for children is affected by monetary issues on a number of different levels. Likewise, travel expenses have been shown to increase the costs of providing and obtaining health care. Bodydell, Pong, Volpe, Tilleczek, Wilson et al argue that patients/caregivers especially those in rural communities travel long distances to access care which entails high transport costs and this creates more difficulties with keeping appointments and adhering to therapeutic regimens.

2.10.2 Travelling distance

Studies have found that location of the health facility and geographical accessibility to these facilities remains a central determinant of participation and continuation of the treatment regimen by the patient or caregiver. It is said that the distance needed to travel to and from treatment imposes costs on patients/caregivers in the form of both greater time commitment and increased economic expenses that affects compliance with the required prescribed treatment (Beardsley, Wish, Fitzelle, O'Grady and Arria (2003). Evidence indicates that there is a relationship between distance to treatment and the length of stay in the treatment regimen. For example in a cross-sectional study on factors associated with treatment adherence among patients with tuberculosis in Thailand, Tornee, Kaewkungwal, Fungladda, Silachamroom, Akarasewi et al (2005) found that the longer the distance a patient had to travel to a health facility, the lower the adherence to the treatment regimen.

Similarly, Reif, Golin and Smith (2005), in a study on barriers to accessing HIV/AIDS care in North Carolina USA, found that 58% of participants indicated long travelling distance and lack of transportation services as their main barrier to adhering to the required treatment protocol. In another study on access and discontinued mental health care among adolescents in Minnesota USA, Samargia, Saewyc and Elliott (2006) found inability to pay for the health services and lack of transport as perceived barriers that hindered adolescents from utilizing and complying with the treatment requirements of mental health. Results from these studies indicate that the location of a health facility from the homes of patients/caregivers can determine the utilisation of medical services from the health facility. On the other hand, transit time may also affect compliance to treatment. A study by Bero, Liiasellg, Lulz, Hanson, Luna, Telxelra and Trajman (2006) on compliance of patients to tuberculosis treatment in Brazil, found that poor patients who experienced longer transit time to reach health facilities, reported symptoms that had lasted significantly longer and had more high rates of previous defaulting than those of their wealthier counterparts.

Studies in developing countries with low-resource settings have shown that multiple barriers affect patient or caregiver's utilization of health care services. In a study in Ghana, Tolhurst and Nyongator (2006) found that distance travelled to health facilities, cost of treatment, long waiting times and negative attitudes of health care providers were major barriers to utilization of health care services. This is consistent with the findings of Oliva, Munoz, Lynch, Mkocha and West (1997) in Tanzania, where it was found that long distances together with high transportation costs to the health facility affected utilization of surgical treatment for patients with trichiasis, and also affected compliance of patients to the required treatment.

2.10.3 Social/family support

According to Letvak (2002), social support is a multidimensional process operationalised on the basis of who is providing the support, quantity and quality of support, availability of support and satisfaction with the support. In this regard, Letvak defines social support as support volunteered by family members and friends. However, Cunningham and Barbee (2000) cited in Letvak 2002 describes social support as a set of people from whom an individual can reasonably expect to receive help in a time of need. This help may be financial assistance or physical assistance during the time of care.

According to Hanneman and Blacher (1998), one of the ways in which families with children that have physical and mental impairments buffer stress is through the use of support systems for instance friends, immediate family members, other relatives or professionals such as social workers, counsellors and others. They suggest that the purpose of support systems is to alleviate strain related to care giving, strengthen or improve family functioning and to improve the quality of life of the parents/caregivers and that of the patient. Furthermore, Letvak (2002) indicates that people with high levels of social support experience less stress when in stressful situations and are able to cope more successfully during difficult times than those without social support

Research by Kadzin and Wassell (2000) and Letvak, (2002) has shown that the development of strong social support networks within the family is a strong predictor of

well-being and health within the family and facilitates follow up for the required treatment. For example, a study by Chen and Tang (1997) in Hong Kong on stress appraisal and social support of Chinese mothers of children with intellectual disability demonstrated that mothers who received tangible, emotional and informational support from family members and training centre staff were more likely to cope with the stress of caring for a child with intellectual disability and follow up with treatment sessions than those parents who did not receive this support. Similarly, Arcury, Preisser, Gesler and Powers (2005), in a study on health care utilisation in twelve Western North Carolina counties in USA, found that respondents with a family or friends who could provide support with transportation attended the prescribed treatment regimen more often than those who did not. In summary, these findings indicate that family support in form of financial or physical support during care, which results in family well being and functioning, is a strong predictor of adherence to treatment requirements.

2.10.4 Communication between clinician and parent

One of the factors that can contribute to defaulting treatment appointments is the way patients/caregivers perceive health care providers (Buck, Jacoby, Burker and Chadwick, 1997). Buck et al argue that if a health provider is perceived as concerned, and prescribes treatment as a reflection of that concern, then the compliance of patients to the prescribed treatment is likely to be higher than if the prescription is seen as an indication that the health provider has no time for or interest in the patient or caregiver. Furthermore, the amount of contact patients have with their health provider may also be an influential factor in enhancing compliance with the prescribed treatment. For example in one study conducted on patients with epilepsy in USA, Buck et al (1997) found that patients who had a regular arrangement to see their physician about epilepsy had a better compliance with the treatment regimen than those who saw the physician irregularly.

According to Iroch-Omale (2004:79), explaining about the problem is a component of communication that requires clarification about the problem, procedures and statements and also the health worker being prepared prior to actual explaining. Kyngäs (1999)

postulates that good communication skills, listening to patient's needs and tailoring treatments to the needs of the patient helps to establish a two-way flow of information that enables the negotiation of a contract of management between the health provider and the patient or caregiver. Similarly, Bultman and Svarstad (2002) assert that proper clinician communication does not only influence patient or caregiver's knowledge about treatment but also changes his or her initial beliefs about the effect of treatment.

According to Van Wieringen, Harmsen and Bruijzeels (2002), health providers and patients/caregivers hold different views and models for illness or disease. They suggest that it is vital to explore the patient/caregiver's explanatory model for illness during consultations and, to try and bridge the gap between the patient/caregiver's and health provider's conception of the health problem, which can only be achieved through effective communication with the patient/caregiver. For example, in a study in New York USA on delayed or forgone care for children with special health care, Smaldone, Honig, and Byrne (2005) found that parents whose health care provider never or only sometimes spent adequate time with them, or listened to their concerns were more likely to forgo care than parents whose health care provider spent adequate time with them or listened to their concerns.

Studies have shown that behaviours of health care providers during treatment can influence patient or caregiver's adherence to the prescribed treatment program. According to Duong, Binns and Lee (2004), health provider-patient interaction has a major impact on the perception of the quality of services rendered and in turn the utilization of health services. Good health provider attitudes towards patients have been found to act as an enabling environment that enhances health provider-client relationship that results in satisfaction with the treatment given and more committed clientele (D'Ambruoso, Abbey and Hussein, 2005).

On the other hand, poor provider-patient interaction is reported to be a barrier to accessibility and utilization of health care services in many African countries (Grossmann-Kendall, Filippi, De Koninck and Kanhonou, 2001). For example in a study

in Kenya, Sharkawy, Newton and Hartley (2006) found that parents of children with epilepsy who had unpleasant or unsuccessful experiences with health care providers in health care facilities stopped taking their children to these health centres for treatment. Similarly, Izugbara, Etukudou and Brown (2005) found that the negative attitudes of health care providers towards patients in public health facilities in Nigeria that arose from frustration, lack of incentives and inadequate materials to use as well as poor remuneration, demoralised patients and caregivers and resulted in them defaulting for treatment appointments. In another study, in Benin, Grossmann-Kendall et al (2001) found that abusive behaviours of health providers in public health care facilities stopped women utilizing and attending to antenatal check ups in public health facilities.

In summary, good communication between the patient/caregiver and the health provider during clinical encounters and consultations is important for mutual understanding and agreement and is a good predictor of compliance to the prescribed care.

2.10.5 Waiting time

Patients and caregivers like to wait for treatment for as short a time as possible. According to Lonroth, Tram, Thuong, Hoang and Diwan (2001), treatments regimens with repeated visits and long waiting times at each visit are inconvenient for the patient and caregiver and are less likely to be attended to as required. Health economy studies have shown that short and long-term absences from work as a result of an excessive treatment wait may result in production losses and this may be a cost to the individual's family and the employer. According to Terricone (2006), the value of lost production as a result of time spent attending treatment at the health facility affects the family in terms of loss of time from paid work and unpaid work and the value (to the caregiver) of leisure activities forgone in terms of quality of life. In addition, according to Waseem, Ravi, Radeos and Gauti (2003), evaluating waiting time for paediatric treatments may be important because parents or caregivers may become unduly stressed and intolerant of what may seem as an excessive wait. Lengthy waiting times tend to cause dissatisfaction with the care, which may lead to poor compliance with the treatment recommendations.

These arguments indicate that the time spent by patients and caregivers in health facilities waiting for treatment is a social cost in terms of lost productivity to the family and may influence the adherence of patients/caregivers to the required treatment.

2.10.6 Parent/caregiver's knowledge

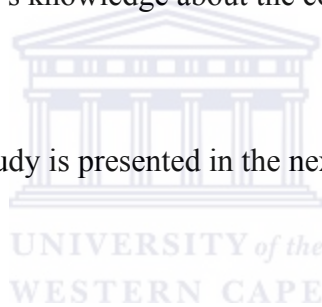
Patient/caregivers default from treatment appointments and at times discontinue treatment due to their poor understanding of the required treatment protocol or not understanding how the treatment works (Bultman and Svarstd, 2002). Levers, Brown, Drotar, Caplan, Pischevar et al (1999) suggest that when health care consumers understand interventions and how these interventions lead to improved health, they are more likely to seek care and adhere to recommended a treatment protocol. O'Callaghan, McAllister and Wilson (2005) argues that increasing health knowledge and awareness among patients/caregivers about their conditions enables them to make informed decisions regarding their health needs.

Similarly, Weiss, Finkelstein, Waters, Mukher, Jee et al (2003) suggest that knowledge about the condition may be a motivation to abide by the treatment regimen in that a person who makes an effort to learn about an illness, will also make an effort to control it. In a study on knowledge of diabetes and adherence to diabetes control measures in France, Fediaevsky, Chwalow, Rufi, Trifunovic, Constans et. al (2005) found that all patients who were knowledgeable about glycaemia control adhered to the recommended treatment regimen unlike those patients who were less knowledgeable. Similarly, in another study on HIV related knowledge and adherence to antiretroviral therapy in New York, USA, Weiss et al (2003) found that all the patients that participated in their study had good knowledge about HIV and complied well with the treatment regimen. In conclusion it could be argued that knowledge about clubfoot and the nature of its treatment interventions may play a role in the compliance with rehabilitation interventions. This could be attained through health education sessions for the parents at the Talipes Clinics structured in form of talks/discussions and, designing pamphlets about clubfoot and its treatment in local languages for parents.

3.0 Summary

This literature reviewed in this chapter has shown that parents and caregivers compliance to the treatment regimen is crucial in determining the success and effectiveness of clubfoot treatment intervention. This review explored issues related to clubfoot: its incidence, patho-anatomy and treatment, compliance of parents/caregivers to treatment and its measurement. In addition, this review has looked at the importance of parents complying with clubfoot treatment and the consequences of poor compliance or adherence to the treatment protocol. A number of factors that act as barriers have been discussed and these include: include financial constraints; accessibility of health care facilities and services; social/family support; communication between the clinician and patient/caregiver; waiting time at the Talipes Clinics; negative attitudes of health care providers; and patient/caregiver's knowledge about the condition.

The methodology used in the study is presented in the next chapter.



CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter discusses the methodology used in this study. It describes the research setting, the study design, the study population, the study sample, the research instrument, the pilot study, the procedure, and the data analysis. The chapter ends with the ethical considerations.

3.2 Research setting

The study was conducted in Uganda, at the Talipes Clinics of Mbarara Regional Referral Hospital and Mulago National Referral Hospital. Mbarara Regional Referral Hospital is the largest hospital in western Uganda with a bed capacity of 360 beds and, serves the districts of Mbarara, Ntungamo, Kiruhura, Rakai, Bushenyi and Kazo (see map 3.1). However, patients are also referred from other district hospitals including hospitals in Kabale, Kasese, Kisoro and Sembabule. Mbarara Regional Referral Hospital has well-established departments of paediatrics, gynaecology and obstetrics, surgery, orthopaedics, dermatology and internal medicine with well-structured outpatient departments for each of the above-mentioned departments. Mulago Hospital is the biggest referral hospital in Uganda and its located in Kampala, which is the capital city of Uganda. The hospital receives patients that are referred from hospitals, health centres, dispensaries and clinics within the city centre and from district hospitals all over the country. Mulago Hospital has a bed capacity of 968 beds and serves the districts of Kampala, Wakiso, Kayunga, Mpigi, Mukono, Luweero, Nakasongola, and Kiboga.

parents have to pay (15000/= Uganda shillings equivalent to R50.0) for foot abduction braces that are used to maintain the correction after the plaster casting stage. Orthopaedic clinical officers (OCOs) and orthopaedic surgeons manage the Talipes Clinics in both hospitals. In Uganda, OCOs are paramedical practitioners who receive a three-year basic training in orthopaedics, medicine and surgery after leaving advanced secondary school. OCOs work with orthopaedic surgeons in referral hospitals and, with general medical officers in district hospitals to reduce fractures, apply plaster casts and provide treatment to patients with other orthopaedic conditions. At Mulago Hospital, in addition to OCOs and orthopaedic surgeons, students from Makerere University Medical School and those from the School of Orthopaedic Clinical Officers are placed at the clinic as part of their clinical and practical experience, who also helps to run the clinic. At Mbarara Regional Referral Hospital, the clinic is operated by OCOs and an orthopaedic surgeon, together with students from Mbarara University Medical School, who are placed at the clinic for their clinical and practical experience. However, some new patients with clubfoot report directly to the physiotherapy department for correction. These patients are often assessed by the physiotherapist, who takes them to the Talipes clinic for correcting the deformity together with the OCOs.

The Talipes Clinic at Mulago Hospital is housed in the surgical outpatient clinic and is open every Thursday. The Talipes Clinic in Mbarara Regional Referral Hospital is housed in the plaster room located in the outpatient department and operates on Tuesday.

According to the clinic records from the Talipes Clinic in Mulago Hospital, most children with clubfeet treated at the clinic are referred from the maternity ward and Mulago Paediatric Clinic. However, children are also referred to the clinic from other hospitals, health centres and clinics within Kampala district and other neighbouring districts. Some parents refer themselves on learning about the availability of the services at Mulago Hospital through their colleagues, awareness programs in the community or through the media. Similarly, at the Talipes Clinic at Mbarara Regional Referral Hospital children with clubfoot are referred from the maternity ward in the hospital; the paediatric outpatient clinic; the health centres in the district; or from district hospitals in the

neighbouring districts. Clinic records at the Talipes clinic at Mbarara Regional Referral Hospital indicate that 220 children with clubfoot were seen in 2004. Of these, 171 children were from rural areas whereas 49 children were from urban centres. However for Mulago Hospital, the researcher could not access the clinical records for all clinics held at the Talipes Clinic in 2004 to identify the total number of patients that were seen.

3.3 Study design

This study used quantitative methods using a cross-sectional descriptive survey. According to Hicks (2004), quantitative responses are easily aggregated for analysis because they are systematic and easily presented in a short space of time. Mouton (2001) recommends use of the quantitative design if data from a large number of people is needed so that a general overview of the group can be obtained. In addition, this design provides baseline data upon which other studies can be built. Therefore this research design suitably addresses the objectives of this study.

3.4 Study population

The study population were parents and caregivers of children with congenital clubfoot deformity. Both male and female parents were recruited from the Talipes Clinics of Mulago Hospital and Mbarara Regional Referral Hospital to participate in the study. Prior to the study, clinical records of the Talipes Clinics at Mbarara Regional Referral Hospital and Mulago Hospital of 2004, indicated that the Talipes Clinic of Mbarara Regional Referral Hospital registered on average four to five parents and their children at each clinic session while that of Mulago Hospital registered on average 21-30 parents and their children at each clinic session. This suggested that over six weeks, the Talipes Clinic in Mbarara Regional Referral Hospital would register between 24 to 30 patients and in Mulago Hospital, the Talipes Clinic would register between 126 to 180 patients. This suggested a study population between 150- 210 parents/caregivers that could be accessed within the period of six weeks the researcher had for data collection. Six weeks of data collection were thought to be adequate to capture a representative sample of

parents of children with clubfoot that were attending the Talipes Clinics at the two hospitals because the whole plaster casting phase takes a period of five weeks.

3.4.1 Sample of convenience

All parents/caregivers with children having clubfoot, who were available at the Talipes Clinic, during the time the study was conducted and, met the inclusion criteria, were included in the study.

The rationale for the inclusion criteria was to include parents/principal caregivers who were bringing their children for treatment and were following the treatment of their children. On the other hand, all relatives who were not principal caregivers and, children that had clubfoot with other deformities, such as spina bifida, were excluded from the study.

3.4.2 Inclusion criteria

- Parent/principal caregivers of children with clubfoot.
- Children with clubfoot between 0-7 months of age undergoing plaster casting treatment.
- Parent/principal caregivers who had been bringing their children for plaster casting.
- Both or either of the parents that was available at the Talipes clinic at the time the study was conducted and was following the treatment of the child.

3.4.3 Exclusion criteria

- Parent/caregivers of children with clubfoot diagnosed by the OCOs, Orthopaedic surgeon or by the physiotherapist with other additional disabilities.
- Other relatives who were not principle caregivers of children with clubfoot.

3.5 Research Instrument

The study utilized a closed ended self-administered questionnaire. The questionnaire was a non-standardized instrument because no standardized questionnaire that meet the

specific needs of this study could be found. A list of questions was generated through reviewing literature and sample questionnaires from relevant articles. The questionnaire (see Appendix 1) consisted of 32 closed ended questions. Ten closed ended questions were adapted from a patient satisfaction questionnaire used by Grogan, Conner, Norman, Willits and Porter (2000) in Scotland. These questions that were adapted from the above-mentioned questionnaire were seen to be suitable for providing responses that could be used to achieve some of the objectives of the study. The questionnaire of Grogan et al (2000) used a number of statements with responses that were coded on a 5 point Likert scale including strongly agree, agree, neither agree or disagree, disagree and strongly disagree. The other 22 questions of the instrument were developed based, firstly, on a review of literature on compliance/adherence of parents/caregivers to treatment regimens and, secondly, on the experience of the researcher within the field of clubfoot treatment.

The final questionnaire that was used in this study included socio-demographic variables such as age and sex of the parent, age of the child, marital status, level of parent/caregiver's education, parent/caregiver's employment status. Questions 12, 13, 14, 15, 22, 23 and 26 were about parent's knowledge about clubfoot. Questions 16 and 24 were about communication between the parent and the clinician. Questions 18, 19, 28, 29 and 30 were about barriers parents encountered in attending treatment appointments whereas questions 31 and 32 were about the role of parents during treatment.

The treatment compliance or adherence was measured by parental report. To verify the verbal responses, they were crosschecked with the documented dates of attendance at treatment appointments at the clinic on the treatment/medical form that is given to the parent/caregiver at the clinic.

3.5.1 Validity of the instrument

The validity of an instrument is described as its ability to measure what is supposed to be measured in conformity with theoretical values (Sarantakos, 1997:78). A valid measure produces true results that reflect the true situation and conditions of the environment it is

supposed to study. Validity is the extent, to which a measure estimates the true nature of what it is purporting to measure (Hicks, 2004:243). This suggests that an instrument should measure exactly the same quality or attribute each time it is used.

The study instrument was developed specifically for this study and had not been previously validated. However, in devising the questionnaire, the researcher attempted to assess its face and content validity by seeking expert opinion to identify ambiguities that could be removed or questions that did not contribute to the study's purpose. The expert reviewed the instrument to assess content areas, the clarity of questions, the instructions and the answers. The expert commented on the wording of the questions and the instructions. The statements adapted from Grogan et al (2000) questionnaire were confusing and did not bring out the meaning of what was intended to be measured after translation into Luanda and Lunyankole languages. These statements were changed into questions. Likewise, the 5-point Likert scale responses to the statements adapted from Grogan et al (2000) questionnaire were too confusing to use after translation into the indigenous languages of Luganda and Lunyankole. These responses were also changed into "Yes" or "No" answers to correspond with the formed questions.

3.5.2 Reliability of the instrument used

Reliability of an instrument is its ability to produce consistent or same results each time it is administered to different groups of respondents (Sarantakos, 1997: 83). During the development of the questionnaire, the researcher tested the instrument (the English version) with 10 parents at the orthopaedic outpatient clinic at Mbarara Regional Referral Hospital before the start of the actual study. The parents selected were of different ages, sexes and had different academic backgrounds. Their responses to the questions differed in the way they: (i) interpreted the meaning of the questions and, (ii) understood the grammar that was used in the questions. Their recommendations were used to make changes to the questionnaire including the order of questions and grammar used in some of the questions. The revised questionnaire was administered to the same parents a week later. Similar steps to those taken in the first administration procedure were followed. At the end of the second test, the parents were convinced with the changes that had been

done to the questions and suggested no further changes. This indicated that appropriate language and correct grammar was used in the questions. This suggested stability and reliability of the instrument.

3.5.3 Translation of the questionnaire

Two specialists in linguistic services translated the questionnaire into two local languages, Luganda and Lunyankole, prior to the pilot study (see appendix 2 and 3).

This was done to ensure that the translated questionnaires in Lunyankole and Luganda expressed what the English version intended to assess. Lunyankole is the official local language used in Mbarara Regional Referral Hospital whereas Luganda and English are widely used in Mulago Hospital. Two other linguistic specialists different from those used at first, were used to translate the questionnaires from Lunyankole and Luganda back to English, to check the possible loss of meaning of the initial English questionnaire.

3.6 Pilot study

A pilot study was conducted with a sample of 10 parents in OURS Rehabilitation Centre (Ruharo) situated in Mbarara town to establish if all the terms used were clear and how long it took a parent to complete the questionnaire. The study was done to familiarise the researcher with the administration of the instrument, and also to assess the parents' understanding of the questions.

Prior to the pilot study, permission to conduct the pilot study was obtained from the project manager of OURS Rehabilitation Centre (Ruharo) to have access to the centre for the pilot study. The written permission (see Appendix 4) was granted and the pilot study was conducted on 30th November 2005 at OURS Rehabilitation Centre (Ruharo). This Rehabilitation Centre has a clinic where treatment of children with clubfoot takes place, similar to the Talipes Clinics in Mbarara Regional Referral Hospital and Mulago Hospital.

The procedure for the pilot study was carried out with a convenient sample of 10 parents out of the 15 parents who had brought their children for plaster casting. Five parents were

excluded because three of their children, in addition to clubfoot, had spina bifida, and the other two had other congenital deformities of the forearm. However, all these parents that participated in the pilot study were not recruited in the main study. The researcher briefed parents about the purpose of the study.

The researcher informed parents that the purpose of the study was to identify obstacles they experienced in attending the clinic for following up the treatment regimen of their children. It was explained that their responses would be used to make revisions in the questionnaire that was going to be used in the main study. These results would be used to improve service delivery and treatment of children with clubfoot at Mbarara Regional Referral Hospital and Mulago Hospital Talipes Clinics. The parents were verbally asked for their consent to participate in the pilot study. Those who voluntarily agreed to participate in the study were asked which language they were fully conversant with (English, or Lunyankole) and were provided with the appropriate questionnaire for completion in writing.

The researcher issued the questionnaire to parents in a group. They were given time to complete it in the presence of the researcher. Parents were allowed to ask questions for any clarification of the questionnaire. In addition, parents were given the opportunity to add any further ideas about areas that might be a source of dissatisfaction or remove ideas that were not clear to them. On completion, the researcher collected the questionnaires. The questionnaire was modified using the information collected from the pilot study. This included making changes to some terms such as “health practitioner” and “health professional” to “clinician”. The revised questionnaire was re-tested with the same parents the following week to establish whether the problems that had been identified earlier were corrected. Parents found that the questionnaire was clear and understandable. This revised questionnaire was used in the main study.

3.7 Procedure of the main study

Permission to conduct the study was obtained from the authorities of the two hospitals and from the person in charge of the Talipes Clinics. The researcher introduced himself

to the parent/caregivers as a group that were waiting for treatment. The parents/caregivers were briefed about the purpose of the study, the importance of their participation in the study and the procedure that the study would follow or use.

Parent/caregivers were informed that the purpose of the study was to identify obstacles they experience in attending the clinic for follow up appointments according to the treatment regimen. They were told that the results of the study would be used to improve service delivery and treatment of children with clubfoot at the clinic. Parent/caregivers were asked individually the age of the child, whether the child had any other impairment in addition to clubfoot and if they were the parent or principle caretaker of the child. Parents who had children of seven months of age or less, and parents of children with only clubfoot deformity and those who were biological parents or principle caregivers were approached and requested to participate in the study. Those who voluntarily agreed to participate in the study were recruited.

Parents/caregivers who gave consent to participate in the study were asked in which language they were fully conversant (English, Luganda or Lunyankole) in order to complete the appropriate questionnaire in writing. However, for unknown reasons, almost all parents/caregivers from the two hospitals wanted to have the questions read to them and give verbal responses. They wanted the researcher to tick the appropriate answer on the questionnaire. This could have resulted in bias to responses parents gave. Only 10 parents from Mulago Hospital agreed to complete the questionnaire in writing by themselves. The researcher clarified questions that parents found difficult to understand. Parents were allowed to ask questions during the interview process.

Each interview took 10-12 minutes to complete. Data collection from parents in Mbarara Regional Referral Hospital was done on the 6th, 13th and 20th December 2005 (with a short break of two weeks for Christmas and New Year season holidays), then on 3rd, 10th and 17th January 2006. At Mulago Hospital, data from parents was collected on the 15th then on 22nd December 2005 (with a short break of two weeks for Christmas and new year season holidays), then on 12th, 19th, and 26th January and 2nd February 2006.

3.8 Method of data analysis

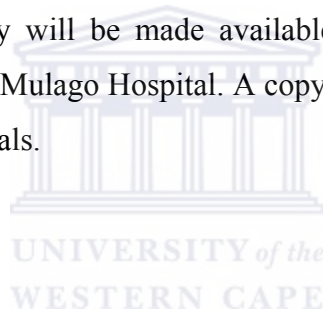
All the responses obtained from the parents were coded numerically and entered into the SPSS version 13.0 software program for analysis. Descriptive statistical analysis was used to calculate the frequencies and percentages. The descriptive analysis of data was presented as figures and tables. Cross tabulation analysis using Pearson Chi-square test was used to determine the associations between compliance of parents to treatment and parent's knowledge about clubfoot treatment; communication between the clinician and the parent; and barriers parents encountered during utilization of services at the clinics and a p-value of less than 0.05 was considered significant.

3.9 Ethical considerations

Permission to carry out the research was granted by the Community Health and Science Faculty and Senate Higher Degrees Committees of UWC. In Uganda, permission to conduct the research in Mbarara Regional Referral Hospital was granted by the Ethics Review Committee of Mbarara University of Science and Technology. The researcher is a member of staff of Mbarara Regional Referral Hospital and was given verbal permission by the chairman of the Ethics Review Commission to start the study at Mbarara Regional Referral Hospital on the 6th December 2005 as written permission was processed. This was done to save time and enable the researcher to collect the required data within the available limited time. Written permission was given on the 7th February 2006 (see Appendix 6). Permission to conduct the pilot study was obtained from the project manager of OURS Rehabilitation Centre (Ruharo) to access the centre for the pilot study (see Appendix 4).

Likewise before commencing the study in Mulago Hospital, verbal permission to gain access and use the Talipes Clinic for the study was granted by the Deputy Director of Mulago Hospital and the in charge of the Talipes Clinic to start data collection on the 15th December 2005 as written permission was processed.

This was also done to save time and enable the researcher collect the required data within the limited available time. The written permission was issued on 16th January 2006. (See appendix 6). Informed verbal consent was obtained from parents that participated in the study. Participation was voluntary. The purpose of the study was explained and the parents assured of the confidentiality and anonymity of the responses, to eliminate their fear that their children's treatment would be affected if, the clinicians could get to know about individual responses. None of the staff working in the Talipes Clinic was involved in the interview process. Names of parents were not recorded on the questionnaires. All the parents were assured of their right to participate, to decline or to withdraw from the study at anytime should they feel uncomfortable. Parents were informed that the information obtained was to be used for research purposes only and would not be shared by any staff of the clinic. There was neither risk of harm to the parents or child or expectations associated with the completion of the questionnaire or participating in the study. The results of the study will be made available to the authorities of Mbarara Regional Referral Hospital and Mulago Hospital. A copy of the thesis will be provided to the authorities of the two hospitals.



3.10 Summary

This chapter discussed the research methodology used in the study. Using a quantitative cross-sectional survey research design, a questionnaire was designed for the study. The study settings were the Talipes Clinics at Mbarara Regional Referral Hospital and Mulago Hospital in Uganda. The questionnaire was piloted at another children rehabilitation centre and changes were made before its use in the main study. Parents preferred to have the questions read to them so that they could provide verbal responses rather than completing the questionnaire themselves. A total of 167 parents were interviewed including 28 parents at Mbarara Regional Referral Hospital and 139 parents at Mulago Hospital. Permission to conduct the study was obtained to gain access to hospitals and clinics. Informed verbal consent was obtained from parents.

The results of the study are presented in the next chapter.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the results of the study. This includes the socio-demographic characteristics of the parents; compliance of parent/caregivers to treatment; knowledge of parents about clubfoot deformity and treatment; communication between clinician and parent; barriers encountered by parents to regular attendance of treatment; and the role of the parent in the treatment of clubfoot deformity.

4.2 Socio-demographic findings

This study aimed to investigate barriers to treatment attendance parents of children with clubfoot encountered in complying with clubfoot treatment during the plaster-casting phase at Mbarara Regional Referral Hospital and Mulago Hospital in Uganda. Two parents/caregivers were excluded from the study in Mulago Hospital because one of the children had hydrocephalus in addition to clubfoot, whereas the other was brought to the clinic by a relative who was not the principle caregiver. A total of 167 parents/caregivers participated in the study in the two hospitals. Twenty-eight parents (16.8%) were recruited at Mbarara Regional Referral Hospital and 139 parents (83.2%) were recruited at Mulago Hospital. Ninety-eight percent of parents (n=164) that participated in the study were biological mothers and 2% (n=3) were biological fathers. There were no caregivers who participated in the study.

This section presents information on the parents' ages, marital status, employment status, and educational level.

4.2.1 Age

The parents' ages ranged from 15 years to 42 years. Their mean age was 27 years, and the mode was 20 years, SD 6.64. The children's ages ranged from two days to 27 weeks. Their mean age was 7 weeks, and the mode was four weeks, SD 5.55.

4.2.2 Marital status

Fifty six percent of parents (n=93) were married, 32% were single parents (n=54), 11% were divorced (n=19) and 1% of parents were widowed (n=1).

Table 4.1 Marital status of parents (n=167)

	Mbarara Hospital (n=28)	Mulago Hospital (n=139)	
Marital Status	(%)	(%)	Total (n)
Single	29	33	54
Married	57	55	93
Divorced	11	12	19
Widowed	3	0	1
Total	100%	100%	167

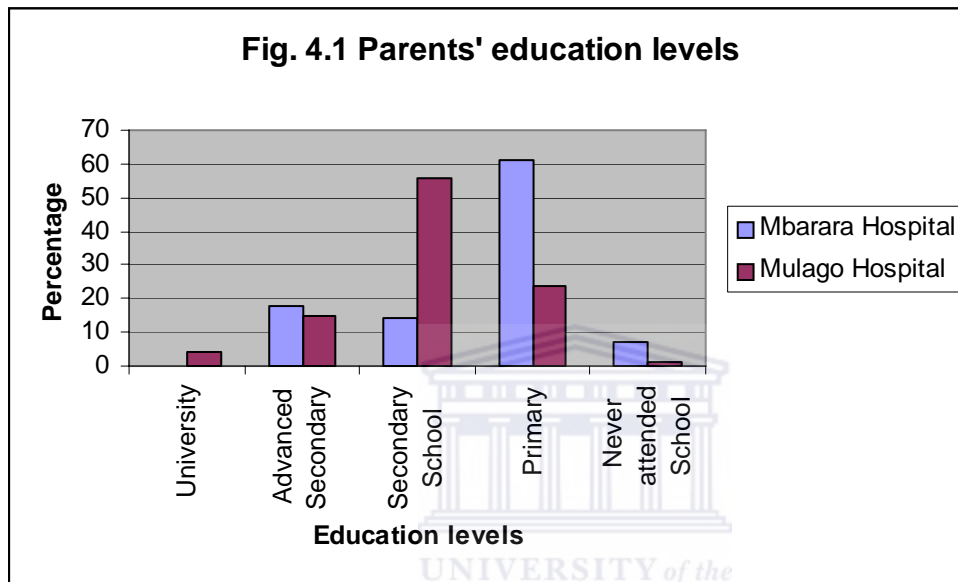
4.2.3 Employment

Forty-three percent of parents (n=73) were employed. This included 16% of parents (n=27) who were in formal employment and 27% of parents (n=46) who were self-employed. Fifty-six percent of parents (n=94) were unemployed. This included 38% of parents (n=64) who were housewives, 12% of parents (n=20) who were single parents and 6% of parents (n=10) who were students.

4.2.4 Education level of parents

In Uganda, there are five levels of education. These include preschool or nursery, primary school level, secondary school level, advanced secondary school level, and tertiary

institutional level, which includes universities and other tertiary institutions. The parents that participated in this study came from different educational backgrounds. 2% of parents (n=4) had never attended school; 30% of parents (n=50) had primary level education; 49% of parents (n=82) had secondary level education, 16% of parents (n=26) had advanced secondary school level education; and 3% of parents (n=5), had University level education.



This pattern of education levels in the two hospitals may be explained by the locations of the two hospitals. Mulago hospital is located in the capital city of Uganda with many institutions of higher education while Mbarara hospital is located in the more rural area.

4.3 Compliance

This section presents the age of the child when the treatment commenced; information on who referred the child for treatment; information on compliance and non-compliance.

4.3.1 Age of treatment commencement

The study identified how soon after the child was born that the treatment commenced. Parents were asked the dates on which they began bringing their children for treatment.

Their responses were compared with the dates that were documented on the appointment cards or treatment forms during the interview, which they were given at the clinic, to confirm their responses. This is presented in Table 4.2

Table 4.2 Age of the child when treatment was started (n=167)

	Mbarara Hospital (n=28)	Mulago Hospital (n=139)	
	(%)	(%)	Total (n)
1-7 days	25	45	69
8-15 days	21	27	43
16-23 days	18	14	24
24-31 days	25	6	16
32-39 days	7	4	8
40-65 days	4	4	7
Total	100%	100%	167

Results show that the mode for when parents brought the child for treatment was seven days after the child was born. SD 12. The youngest age at which parents commenced treatment was two days after the child was born and the latest was 65 days after the child was born. The mean was 14 days after the child was born.

4.3.2 Referral of children to the Talipes clinics

The children who were brought to the Talipes Clinics of the two hospitals were referred from different sources. Seventy-two percent of the children (n=120) were referred by medical professionals, 16% of children (n=27) were referred by friends, 7% of children (n=12) were referred by traditional birth attendants, parents of 4% of children (n=7) referred themselves to the clinic and 1% of children (n=1) were referred to the clinic by other people. This is shown in Table 4.3 where the difference between the two hospitals is presented.

Table 4.3 Referral of children to the clinics (n=167)

	Mbarara Hospital (n=28)	Mulago Hospital (n=139)	
Person referring	(%)	(%)	Total (n)
Medical personnel	57	75	120
Traditional birth attendant	4	8	12
Friend	25	14	27
Self referral	14	2	7
Others	0	1	1
Total	100%	100%	167

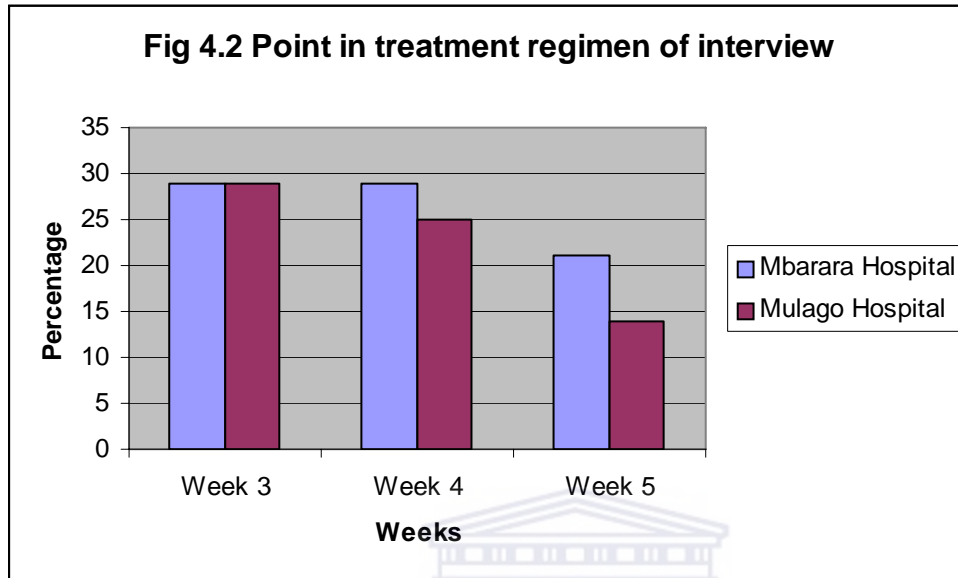
The high percentage of patients referred by medical personnel in Mulago Hospital, the urban setting, compared to that in Mbarara Regional Referral Hospital, the more rural setting, could be that most of these babies were born in Mulago Hospital. On the other hand, children could also have been referred from the private hospitals such as Nsyambya Hospital, Lubaga Hospital, Mengo Hospital, Kampala international hospital, and Kibuli Hospital, which are near Mulago Hospital.

4.3.3 Measurement of Compliance

In this study, information on how regularly the parent brought the child for treatment was used to assess compliance of the parent to treatment regimen. The plaster casting treatment procedure requires a parent to bring the child for treatment once every week for 5 consecutive weeks during the first phase of treatment (plaster casting stage). Parents who were considered to be compliant were those who brought their children for treatment once every week for five consecutive weeks. However, parents who had brought their children once every week for treatment for three or four weeks without missing a single treatment session were also considered to be compliant if their treatment regimen was not yet complete. The researcher was able to interact with most of these parents at two or

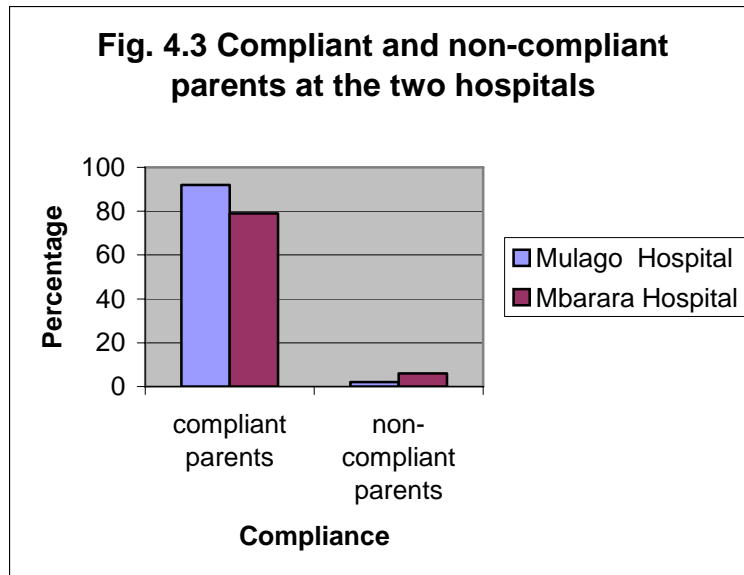
more treatment sessions during the time the study was conducted. This enabled him to assess how they were following the treatment appointments during the study period.

The point in the treatment regimen that the interview took place is illustrated in Fig 4.2



4.3.4 Compliance with treatment

Parents were asked how often they brought their children for treatment except for the ten parents who completed the questionnaires on their own. Out of the total sample, 90% of parents (n=150) that participated in the study at the two hospitals indicated that they brought their children for treatment once a week. That is, these parents attended every treatment session for consecutive weeks. Seventy-nine percent of parents (n=22) at Mbarara Regional Referral Hospital indicated that they brought their children once a week for treatment. Ninety-two percent of parents (n=128) at Mulago Hospital indicated that they brought their children once a week for treatment. These parents were identified as compliant with the treatment or considered to be attending regularly to the treatment regime. The compliant and non-compliant parents are illustrated in Fig 4.3.



Ten percent of parents (n=17) did not bring their children in for treatment every week. Of this, one percent of parents (n=2) indicated that they brought their children for treatment after 2 weeks, 5% of parents (n=8) had missed two treatment appointments and 4% of parents (n=7) did not indicate on the questionnaires how often they brought their children for treatment. Since these parents had not brought their children for treatment on consecutive weekly basis, they were considered not to be attending to treatment regularly.

4.4 Parents' knowledge

This section presents the findings of parents' knowledge of clubfoot and the importance of treatment; their knowledge of the effects of non-compliance; their knowledge of the need to change the plaster; and their knowledge of their role in the treatment of clubfoot.

4.4.1 Parents' knowledge of clubfoot and importance of treatment

Parents were asked their knowledge about clubfoot before and after diagnosis and their view on the importance of treatment after diagnosis. From the total sample, 67% of parents (n=111) indicated that they knew nothing about clubfoot deformity before their child was diagnosed. Sixty-eight percent of parents (n=113) indicated that the clinician had not explained to them what clubfoot was at the time of diagnosis. This included 75% of parents from Mbarara Hospital and 66% of parents from Mulago Hospital. However,

at the time of the interview, 86% of parents (n=147) indicated that they knew why they were following the prescribed treatment regimen. On the other hand, only 12% of parents (n=19) indicated knowing why they had to bring their children for treatment every week. Most of parents, 88% (n=148), indicated that they did not know why they had to bring their children for treatment every week.

As regards to information about treatment, 60% of parents (n=100) indicated that the clinician did not give them sufficient information about treatment. This included 61% of parents from Mbarara Hospital and 60% of parents from Mulago Hospital. However, although most parents indicated that the clinician did not give them sufficient information about treatment, 90% of parents (n=151) indicated that the clinician informed them how to follow the prescribed treatment. This included 89% of parents from Mbarara Regional Referral Hospital and 91% of parents from Mulago Hospital.

However, all parents indicated that it was necessary to attend to treatment as prescribed by the clinician. This is illustrated in Table 4.4, showing the differences between the two hospitals.

Table 4.4 Parents' knowledge of clubfoot and importance of attending regularly for treatment (n=167)

	Mbarara Hospital (n=28)		Mulago Hospital (n=139)	
	Yes	No	Yes	No
Parent knew about clubfoot before diagnosis	2 (7%)	26 (93%)	54 (39%)	85 (61%)
Clinician explained what clubfoot was at the time of diagnosis	7(25%)	21(75%)	47 (34%)	92(66%)
Parent understood why he/she had to bring the child for treatment every week	3(11%)	25(89%)	17 (12%)	122(88%)
The clinician explains what clubfoot deformity is before putting on plaster cast	11(39%)	17(61%)	44(32%)	95(68%)
The clinician gives parents sufficient information about treatment	11(39%)	17(61%)	56(40%)	83(60%)
The clinician informs parents how to follow the prescribed treatment	25(89%)	3(11%)	126(91%)	13(9%)

These results show that most parents in Mbarara Regional Referral Hospital and Mulago Hospital did not know about clubfoot prior to their child's diagnosis; were not explained what clubfoot was by the clinician; and did not understand why they had to bring the child for treatment every week. These results further indicate that there are more parents knowing about clubfoot prior diagnosis at Mulago Hospital than at Mbarara Regional Referral Hospital.

4.4.2 Parents' knowledge of the effect of non-compliance

Despite the inadequate knowledge parents indicated they had about clubfoot and its treatment, most parents understood the consequences of not following the treatment regimen. From the total sample, 74% of parents (n=123) said that irregular treatment follow up would cause the foot of the child to become more disfigured. This included 64% of parents from Mbarara Regional Referral Hospital and 76% of parents from Mulago Hospital. Twenty-two percent of parents (n=37) said that irregular treatment follow up would cause the foot to remain deformed as it was before treatment. This included 25% of parents from Mbarara Regional Referral Hospital, and 22% of parents from Mulago Hospital. Only 4% of the parents (n=7) were not sure of what would happen to the foot of the child with irregular treatment follow up. This included 11% of parents in Mbarara Regional Referral Hospital and 3% of parents from Mulago Hospital. These results also indicate that parents at Mulago Hospital in an urban setting appear to know more about the consequences of not following the prescribed treatment than those at Mbarara Hospital, which is more rural. This may be the result of a more educated sample at Mulago Hospital.

4.4.3 Reasons for changing a plaster cast.

Parents indicated their views on why a plaster cast needs to be changed. Parents were provided with three reasons for changing a plaster and these included: to inspect the foot and skin, stretch the shortened structures of the foot, together with performing exercises to the foot; to allow increase in the size of the foot; and to maintain cleanliness of the foot. These are presented in Table 4.5

Table 4.5 Reasons for changing plaster (n=167)

	Mbarara Hospital (n=28)			Mulago Hospital (n=139)		
	Yes	No	Do not know	Yes	No	Do not know
Inspect and stretch foot and exercises	10(36%)	0	18(64%)	65(47%)	1(1%)	73(53%)
Allow increase in the size of the foot	8(29%)	0	20(71%)	61(44%)	1(1%)	77(55%)

From the total sample, 45% of parents (n=95) indicated that a plaster is changed to allow the clinician inspect the foot, to stretch the foot and perform exercises. This included 36% of parents from Mbarara Regional Referral Hospital and 47% of parents from Mulago Hospital. Similarly, only 41% of parents (n=69) indicated knowing that a plaster cast is changed to allow increase in the size of the foot. This included 29% of parents from Mbarara Regional Referral Hospital and 44% of parents from Mulago Hospital. All parents who participated in the study knew that a plaster cast is changed in order to maintain the cleanliness of the foot. However, 64% of parents from Mbarara Regional Referral Hospital, and 53% of parents from Mulago Hospital, indicated that they did not know that a plaster is changed for inspection, stretching and exercising the foot. Similarly, 71% of parents from Mbarara Regional Referral Hospital and 55% of parents from Mulago Hospital also indicated that they did not know that a plaster is changed to allow increase in the size of the foot. These results also indicate that parents at Mulago Hospital had greater knowledge of why a plaster cast is changed than those at Mbarara Hospital.

4.4.4 Parents' role in treatment

This section presents the findings of parent's knowledge of their role in the treatment of clubfoot during the plaster casting phase.

4.4.4.1 Knowledge of parents of their current role in the treatment of clubfoot

Parents' current roles in the treatment of clubfoot included: bringing the child every week for treatment; and taking care of plaster casts which involved preventing plasters from

being soaked with water, preventing the urine going into the plaster cast, and preventing the child playing on wet floor or ground.

All parents indicated that it was their prime responsibility to bring the child every week for treatment, not to pour water on the plaster cast and, to protect wetting plaster casts with urine from the child. However, as regards to preventing child with plaster cast from playing on wet floor or ground, parents had different views and responses. Seventy percent of parents (n=117) indicated that it was their responsibility to prevent their child playing on wet floor or ground when in a plaster cast. This included 64% of parents from Mbarara Hospital and 71% of parents from Mulago Hospital. However, 29% of parents (n=49) did not know that this was part of their responsibility and this included, 36% of parents from Mbarara Hospital, and 28% of parents from Mulago Hospital.

4.4.4.2 Knowledge of parents of their future role in the treatment of clubfoot

The future role of the parent in the treatment of clubfoot is dressing the child with foot abduction braces after the plaster-casting phase to maintain the correction achieved in the treatment phase. The child is required to wear these braces for 23 out of 24 hours everyday for three months, and for two years at night and nap times only. From the total sample, 79% percent of parents (n=133) indicated that they did not know that it was their responsibility to ensure that the child would wear abduction braces after the plaster-casting phase. This is illustrated in Table 4.6.

Table 4.6 Parents' knowledge of their future role in the treatment of clubfoot (n=167)

	Mbarara Hospital (n=28)			Mulago Hospital (n=139)		
	Yes	No	Do not know	Yes	No	Do not know
Ensure child wears foot abduction braces after plaster caster phase	3(11%)	0	25(89%)	29(21%)	1(1%)	109(78%)

4.5 Parents' views on communication between clinician and parent

The study asked parents about their views regarding their communication with the clinician during treatment as a way of assessing the interaction between the parent and clinician during the treatment process. The results are presented in Table 4.7.

Table 4.7 Parents' experience of communication with the clinician (n=167)

	Mbarara Hospital (n=28)		Mulago Hospital (n=139)	
	Yes	No	Yes	No
The clinician gives a written reminder of attendance dates to the parent	28 (100%)	0	139(100%)	0
The clinician gives a chance for parents to talk about their problems	5 (18%)	23(82%)	56(40%)	83(60%)

Results show that all parents in the two hospitals indicated that the clinician gave them written reminders of attendance dates for the clinic. In addition, 64% of parents (n=107) indicated that the clinician did not give them a chance to talk about their problems. This included 82% of parents from Mbarara Regional Referral Hospital and 60% of parents from Mulago Hospital.

4.6 Barriers to regular treatment attendance

Barriers to treatment attendance that might influence the compliance were investigated. The barriers that were assessed include: family support (both physical and financial); transport costs; travelling distance; waiting time at the Talipes Clinics.

4.6.1 Inadequate family support

Two aspects of family support were investigated. These included the physical support provided to the parent at home and the financial support that is required for the parent and the child to attend treatment at the Talipes Clinics.

4.6.1.1 Physical support

The study investigated whether having someone to take care of the other children at home influenced the parents bringing the affected child for treatment at the clinic. Seventy-one

percent of parents (n=118) indicated that they had someone at home to take care of their other children and this was reported as one of the factors that enabled them to bring the child for treatment every week.

4.6.1.2 Financial support

The findings identified who provided the financial support that enabled parents to bring the child for treatment at the Talipes Clinics. This is shown in Table 4.8.

Table 4.8 Source of financial support for the parent (n=167)

	Mbarara Hospital	Mulago Hospital	Total
	(n=28)	(n=139)	
Financial provider	(%)	(%)	(n)
Child's father	64	57	97
Child's mother	21	24	39
Maternal grandparent	7	5	9
Paternal grandparent	4	9	13
Friends	4	0	1
Others	0	6	8
Total	100%	100%	167

Fifty-eight percent of the parents (n=97) indicated that they received financial assistance from the father of the child that enabled them to bring the child to the clinic. This included 64% of parents from Mbarara Regional Referral Hospital and 57% of parents from Mulago Hospital. Twenty-three percent of the parents (n=39) indicated that they met the required finances themselves without any other support. This included 21% of parents from Mbarara Regional Referral Hospital and 24% of parents from Mulago Hospital. Eight percent of the parents (n=13) indicated that they received financial support from the child's paternal grand parents, 5% of parents (n=9) received financial support from the child's maternal grand parents, 4% of parents (n=1) got financial assistance from friends, whereas 6% of parents (n=8) received financial assistance from other sources.

4.6.2 Transport costs

Parents indicated the transport expenses incurred in bringing the child for treatment. Eighty-two percent of parents (n=137) said that they found it expensive to bring children for treatment every week (Qn 18 (i)). The study also asked parents, how much money they were paying for transport to and from the hospital. Results show that the minimum amount of money parents paid for transport was 600/= Uganda shillings (R2.00) and the highest amount was 15000/= Uganda shillings (R50.00) for the return trip. On average parents paid 2804/= (SD = 1877.7) Uganda shillings (R 9.40) for transport. However, the majority of parents who participated in the study were unemployed housewives and it was difficult for them to estimate how much their husbands spent on transport and other medical costs out of their total monthly income.

4.6.3 Travelling distance

Parents covered variable distances from their homes to the hospital in pursuit of treatment for their children at the Talipes Clinics. This is shown in Table 4.9

Table 4.9 Distance parents travelled (n=167)

Return Distance	Mbarara Hospital (n=28)	Mulago Hospital (n=139)	Total (n)
	(%)	(%)	
Less than 5	7	25	35
5-9 miles	14	45	67
10-14 miles	14	25	39
15-19 miles	18	2	8
20-24 miles	18	3	9
25-29 miles	7	0	2
30-34 miles	14	0	4
More than 35 miles	7	1	3
Total	100%	100%	167

All parents who travelled 9 miles or less to hospital were considered to be living near the hospital whereas those who travelled ten miles or more were considered to be living far away from the hospital. Sixty-one percent of parents (n=102) indicated that they lived near the hospital whereas 39% of the parents (n=65) indicated that they lived far from the

hospital. The shortest distance parents travelled was 2 miles and the longest was 80 miles. The mean distance parents travelled to the hospital was 10 miles (SD = 8.9).

Most parents that brought their children for treatment at Mbarara Regional Referral Hospital travelled between 15-24 miles (return trip) where as those that attended treatment at Mulago Hospital, the majority travelled between 5-9 miles. This is because Mbarara Regional Referral Hospital is located in a rural area and most of the patients receiving treatment at this hospital are from rural areas located far away from the hospital with poor road networks and transportation systems. Mulago Hospital is in the city centre and most of the parents who receive treatment from this hospital reside in the suburbs of the city or areas that are near the hospital. The city has a variety of transport systems and good road networks.

4.6.4 Waiting time

Parents indicated how much time they spent in queues waiting for treatment at the Talipes Clinics. It was found that the shortest time parents spent in the clinic was less than 30 minutes, and the longest time was more than 3 hours. However, on average, most parents spent 2 hours in the queue waiting to be attended to (SD=0.83). This is shown in Table 4.11.

Table 4.10 Waiting time at the Talipes Clinics (n=167)

	Mbarara Hospital (n=28)	Mulago Hospital (n=139)	
Waiting time	(%)	(%)	Total (n)
Less than 30 minutes	4	1	2
More than 30 minutes	0	1	2
Approximately 1 hour	14	12	21
Approximately 2 hours	46	57	92
Approximately 3 hours	25	26	43
More than 3 hours	11	3	7
Total	100%	100%	167

When asked what time would be appropriate for them to wait for treatment, most parents suggested one hour to be the most convenient length of time for them to wait for treatment.

4.7 Association between compliance and parents' marital status, family support, travelling distance, cost of transport and waiting time, parents' knowledge about treatment, and communication between clinician and parent

This section presents the findings of associations between compliance with the treatment regimen and parents' marital status, family support, travelling distance, transport costs, waiting time, communication between clinician and parent, and parents' knowledge about treatment. In order to explore the associations, cross-tabulations and Pearson Chi-square statistical tests were used. The significant p-value was established at $p < 0.05$.

4.7.1 Association between compliance and marital status

There was a significant association between compliance to treatment and marital status of parents ($p = 0.001$) indicating that married parents were more likely to attend regularly for treatment than single parents who were more irregular attendees.

4.7.2 Compliance and family support

Family support was assessed using two indicators. One was having someone to take care of other children at home while the parent brings the child to hospital for treatment (physical support), and the other was having some one to provide financial support required for transport and other necessary expenses (financial support).

4.7.2.1 Association between compliance and physical support

There was a significant association between physical support and compliance to treatment ($p = 0.028$). This means that parents who had someone at home to take care of other children were more likely to be compliant with the treatment regimen than their counterparts without this support.

4.7.2.2 Association between compliance and financial support

The study found a significant association between financial support and compliance to treatment regime ($p=0.002$). This indicates that parents who had someone to provide financial assistance or support to meet transportation costs and other extra medical expenses were more likely to be compliant with the treatment regime than those without.

4.7.3 Compliance and travelling distance

This section presents findings of associations between compliance with the treatment regimen and the distances parents travelled to the Talipes Clinics to access treatment.

4.7.3.1 Association between compliance and travelling distance

The study found a significant association ($p=0.005$) between the distances parents travelled and their compliance with the treatment regimen. This indicates that parents who travelled short distances to the clinic were more likely to be compliant than those who travelled long distances.

4.7.4 Association between compliance and transport costs

The costs parents paid for transport (return trip) were divided into two categories for analysis. Costs of 3000/= and less were considered not expensive whereas those between 3000/= and 15000/= (equivalent to R10.0-R50.0) were considered expensive. Parents who spent more than 3000/= an equivalent of (R10.0) on transport reported that it was expensive for them to bring the child to hospital every week. There was a significant association ($p=0.009$) between the costs parents paid for transport and their compliance with the treatment regimen. This indicated that parents who paid less than 3000/= were more likely to be compliant than those who paid more than 3000/=.

4.7.5 Association between compliance and waiting time

Parents indicated how much time they spent in queues waiting for treatment at the Talipes Clinics. The study found no significant association ($p=0.52$) between compliance

to treatment regimen, and waiting time at the Talipes Clinics, implying that waiting time did not influence compliance of parents to the treatment regimen.

4.7.6 Parent's knowledge about clubfoot and treatment

This section presents findings of association between compliance of parents with the treatment regimen and their knowledge about clubfoot and its treatment.

4.7.6.1 Association between compliance and parents' knowledge about clubfoot and treatment

The study found no significant association ($p= 0.14$) between parents' knowledge about treatment (Qns 12, 13, 14, 22 and 23) as a whole and, compliance with the treatment regimen. This indicates that parents' knowledge about clubfoot and its treatment did not influence compliance with the treatment regimen. However, parents who were aware of what would happen to their children if they did not attend for treatment were more likely to be compliant than those who did not know what would happen to the children ($p=0.045$).

4.7.7 Compliance and parents' experience of communication with clinician

This section presents the findings between compliance of parents to the treatment regimen and their communication with the clinician.

4.7.7.1 Association between compliance and parents' experience of communication with the clinician

Two questions (16 and 24) were used to determine the parents' reported experience of communication with the clinician. There was no significant association ($p=0.26$) that was found between compliance of parents to the treatment regimen and their experience of communication with the clinician. However, parents who were given a chance to talk about their problems were more compliant with the treatment regimen than parents who were not given this opportunity ($p=0.022$).

In summary, there was a significant association between compliance and being married; compliance and getting physical and financial support from the family; compliance and a

shorter travelling distance; compliance and a lower costs of transport; compliance and knowledge of possible complications of not attending; and compliance and talking about problems to the clinician. There was no significant association between compliance and parents' knowledge about clubfoot and its treatment; and compliance and parents' reported experience of communication with the clinician.

4.8 Summary

This chapter has presented the results of the study including socio demographic characteristics of the participants, their age, marital status, education status, and employment status. The chapter presented parents' knowledge of clubfoot, its treatment, and the role of parent in the treatment, their interaction with the clinician during treatment, and barriers that parents encountered in complying with the treatment regimen. Associations between compliance and the different barriers to treatment were also determined. Compliance of parents to the treatment regime was found to be high (90% of parents were compliant).

However, although most of the parents that participated in the study were compliant with the treatment, results show that most parents did not know about clubfoot, and were not informed about its treatment. Similarly, parents were not given a chance to tell clinicians about the problems they met in following the treatment regimen. The results show that most parents attending treatment from Mulago Hospital live less than 9 miles from the hospital. Most parents indicated that they found it expensive to bring their children for treatment every week. There was a significant association between marital status, travelling distance, transportation costs, family support and compliance to the treatment regimen. However, despite having spent along time waiting for treatment (approximately 2 hours), the association between compliance and waiting time was not statistically significant.

A discussion of the results of the study is presented in the next chapter.

CHAPTER FIVE

DISCUSSION

5.1 INTRODUCTION

This chapter discusses the findings from parents who brought their children for the treatment of clubfoot at the Talipes Clinics of Mbarara Regional Referral Hospital and Mulago Hospital. In this chapter, the findings are discussed with reference to the aim and objectives of the study, as well as to the relevant literature. The chapter is divided into four sections according to the objectives of the study. These were, firstly, to identify parents' knowledge of clubfoot and its treatment, secondly, to investigate parents' roles during the plaster-casting stage of clubfoot treatment, thirdly, to identify the difficulties parents experience in attending all treatment appointments, and finally, to identify associations between compliance to treatment and parents' knowledge about clubfoot, parents' experience of communication with the clinician, and the difficulties parents experience in attending all treatment appointments.

5.2 Study sample

This section starts with a discussion of the sample. This study investigated compliance of parents of children with clubfoot to the treatment regimen during the plaster casting phase. Results from the study show that the study sample of 167 parents who brought their children to the Talipes Clinics for treatment and participated in the study, consisted of 163 mothers and three fathers. The female gender dominance in this study is consistent with the observation made in a study of caregivers who brought their children at an outpatient treatment clinic for children with psychiatric disorders in USA. Of the 242 subjects who participated in the study, 93.7% were mothers (Kazdin, Holland, and Crowley, 1997). Similarly, Kadzin and Wassell (1999), at Yale child conduct clinic Yale University in USA, observed that of the 200 parents who participated in the study on barriers to treatment participation, 93% were mothers and 7% were other relatives. However the mothers in this sample that was used by Kadzin and Wassell were highly

educated and resided in financially stable families unlike those that were recruited in the current study.

It can be argued that the female gender in the sample dominated because of gender roles. Globally, women take the role of care taking for children and attending for their children's medical appointments. Traditionally women in many African families are expected to perform domestic activities, nurture children and care for the sick whereas men perform the role of breadwinner and provider of the necessary resources to the family. As a result for economic reasons, men are less likely to take the child for treatment. During the time when treatment is given to the child, men are expected to be busy earning a living for the family and so unable to take time out of work.

In most studies that involve caretakers or parents, participants are largely female because women tend to assume the primary burden of care and male carers are usually at work during the day when treatment is offered to the children (Williams, Cullen and Barlow, 2005). However, with increasing numbers of educated women, gender roles are changing with women increasingly becoming providers as well as carers. This is however, taking place without a corresponding change in men's behaviour in these areas traditionally seen as women's responsibilities such as caring for children and the sick (Tolhurst and Nyonator, 2006).

However, it needs to be noted that the study sample included parents who were compliant with the treatment. Due to financial constraints and geographical inaccessibility, non-compliant parents were not interviewed and were not traced for inclusion within the limited time the study was conducted. The gender bias in the study sample could be that mothers were more concerned with the condition of the children and were more interested in seeing the condition corrected than the fathers. On the other hand, mothers could have had more time to attend to the treatment appointments than the fathers and this also could have led to the biased gender distribution in the study sample.

In addition, results showed that married parents were more likely to attend regularly for treatment ($p=0.001$) than single parents who were more irregular attendees. This could be because married parents have support from the other parent in the day-to-day care of the child during treatment so that mothers are not strained alone with the burden of care. For instance fathers could provide both financial support by meeting transportation costs to and from the hospital, and physical support by taking care of other children in the home as the mother attends to treatment in the hospital and the father helping her with the domestic work during the period she is at the Talipes Clinic, which might not be the case with single parents.

5.3 Commencement of treatment

In this study, most parents who participated in the study 41% ($n=69$) commenced treatment before the baby was one week of age. Most parents indicated that the children were referred to the Talipes Clinic from the maternity wards of the two hospitals immediately after birth. So it is likely that mothers of these children would attend the treatment of the child. It has been shown that treatment initiated immediately after birth corrects most clubfoot deformities in a relatively short time without the need for surgery (Ponseti, 1997). It could be argued that the medical staff at the maternity wards from where most of these children came, were aware of the benefits of starting treatment early in a child's life and, they may have informed these parents about these benefits. This could have motivated them to start treatment early, and also follow up the treatment appointments, resulting in them becoming compliant with the treatment regimen. In Mbarara Regional Referral Hospital and Mulago Hospital, mothers who give birth normally are kept in the hospital for 48 hours while under observation before discharging them whereas those who undergo caesarean operations are kept for two weeks or longer. It could be that the medical staff utilized this time and referred these children to the Talipes Clinics to start early treatment before discharging the mothers.

5.4 Compliance of parents to the treatment regimen

In this study, compliance to treatment was described as the parents' ability to bring the child for plaster casting every week for five to six weeks of treatment as suggested by the clinician. Compliance to treatment in this study was measured by parental report on

keeping treatment appointments at the Talipes Clinics, and cross checking with dates of treatment sessions attended as documented on treatment forms given to parents at the clinic, to confirm their verbal reports.

Results from the study indicate that 90% of parents who participated in the study at the two hospitals indicated that they brought their children for treatment every consecutive week and so were considered compliant. Fifty-five percent of parents (n=92) out of the total sample were in their third or fourth week of treatment, and 16% of parents (n=26) were in their fifth week in the treatment regimen. This further suggests that most parents were attending the treatment appointments of their children as was required.

It could be argued that the good compliance was because most participants were women. Women are expected to take the role of care taking seriously and appear to do so by trying to fulfil treatment requirements so that their children can improve (Owens, Hoagwood, Horwitz, Leaf, Poduska et al (2002). It is not known whether, if their husbands were not working, they would have brought the children consistently or would have complied with the treatment regimen. This finding in relation to responsibility taken by men and women needs to be explored more fully with parents that access treatment of clubfoot at the hospitals both in rural and urban areas in Uganda.

The results of this study are consistent with other studies on compliance of parents. In a study in Saudi Arabia on compliance with treatment appointments and medications in paediatric neurology by Al-Faris, Abdulghani, Mahdi, Salih and Al-Kordi (2002), of the 147 parents that participated in the study, 86% reported that they were complying with the use of the medication and keeping treatment appointments. A similar study in Israel on compliance with the prescribed rehabilitation therapy in Jewish and Bedouin populations, by Gail et al (2001), found that 89% of the 110 Jewish parents and 78% of the 83 Bedouin parents that participated in the study reported that they complied with the exercise treatment regimen.

One other factor that could have contributed to the good compliance is improvement in the condition. At each visit to the Talipes Clinic, the clinician removes the old plaster cast

from the child, stretches the foot to a more correct and near to normal position, and reapplies the cast. At each successive treatment, the structure of the foot often looks better than the previous one. Potter, Gordon and Hamer (2003) argue that improvement in the condition is the most important outcome patients and caregivers expect to achieve during treatment. They argue that improvement in the condition is a vital factor motivating patients and caregivers to adhere to the recommended treatment requirements.

It could be argued that the small improvement in the correction of the structure of the child's foot that parents observe during each treatment session motivates them to attend every treatment session in anticipation of complete correction.

The findings in this study are in complete contrast to a study by Scott and Evans (1997) on management of clubfoot at St Francis Hospital in Tanzania. This indicated that of the 26 patients with idiopathic clubfoot who were recruited and treated with manipulations and plaster casting, less than ten patients were brought to the clinic for follow up treatment on more than three occasions. All patients were lost to follow-up prior to satisfactory result being obtained. This indicates that the majority of patients were non-compliant with the treatment regimen and, also shows how adherence to treatment that requires consecutive multiple attendances at health facilities can be difficult in some societies. This shows that it is important to explore the reasons for non-compliance in parents or caregivers, so that parents who are not compliant can be helped and motivated to adhere to the treatment regimen, so that their children receive consistent treatment. This will improve the effectiveness of the treatment and, will reduce clubfoot disability in the community.

5.5 Parents' knowledge of the importance of treatment

The second objective of this study was to identify what parents knew about clubfoot and its treatment. Public health planners have recognized the importance of health workers being informed about the knowledge and perceptions which people hold regarding health and illness, causes of disease and possible remedies (Dyer, Abraham, Hoffman and Van der Spy, 2002). Theorists have proposed that a mismatch between the patient/caregivers'

and the therapist's expectations for treatment may lead to dissatisfaction with services and may lead to poor adherence to the treatment regime (McCabe, 2002). For instance if patients/caregivers have little knowledge about the condition and are unfamiliar with the process of treatment, they may have unrealistic expectations about how long the treatment will last, how quickly their child's problem will resolve, and to what extent they will be expected to participate in treatment (McCabe, 2002).

In this study, 67% of parents (n=111) indicated that they knew nothing about clubfoot before their child was diagnosed. However, 87% of the parents (n=147) indicated that they knew why they were following the prescribed treatment although 71% of the parents (n=113) indicated that the clinician had not explained to them what clubfoot was at the time of diagnosis. A greater proportion of parents at Mulago Hospital knew; about clubfoot prior diagnosis; the consequences of not following the prescribed treatment; and had greater knowledge of why a plaster is changed than those at Mbarara Regional Referral Hospital. This difference can be contributed to a more educated sample at Mulago Hospital and, more exposure of these parents to information about clubfoot than their counterparts in Mbarara Regional Referral Hospital.

Similarly, 79% percent of parents (n=133) indicated that they did not know that it was their responsibility to wear the child with abduction braces after the plaster casting phase. This included 89% of parents from Mbarara Hospital and 78% of parents from Mulago Hospital. This high percentage of parents indicating they did not know of their future responsibility was probably because their children were still undergoing plaster casting, and medical personnel had not informed them of the next stage of treatment. However, 20% of parents (n=33) indicated that they understood that it was their responsibility to ensure the child wears the foot abduction braces after plaster casting stage. However, parents at Mulago Hospital were more knowledgeable about their future role than those at Mbarara Hospital.

However, despite the inadequate knowledge prior to diagnosis, 74% of parents (n=123) indicated they understood the consequences of not following the treatment regimen. This indicates that these parents learnt about some aspects about clubfoot and its treatment

including the benefits of adhering to the prescribed treatment during the time they attended for the treatment of their children. However it is not known whether this parental learning was through exposure to the treatment or was obtained from fellow parents that had started bringing their children earlier for treatment or those that had undergone several treatment sessions at the clinic.

Research has shown that parental knowledge about the condition may change after exposure to the prescribed treatment (Corkum, Rimer and Schachar, 1999). It could be presumed that parents whose children were starting treatment experienced more doubts and uncertainty about their children's impairment and expected clinicians to clear these doubts and uncertainties. If this opportunity did not materialize, they might have sought some of this information from other parents who had started treatment earlier.

The results of this study are consistent with the findings of Chardwick, Jolliffe and Goldbart (2002), in Manchester, United Kingdom, on caregiver's knowledge of dysphasia and its influence on adherence to dysphasia management strategies. They found that while only 45% of caregivers (n=46) had good knowledge about dysphasia, 77% of these caregivers adhered to the required management strategies of dysphasia. The results of the current study indicate that parents had poor knowledge about clubfoot and its treatment initially but acquired more through successive attendance to the treatment for their children. However, the study found no significant association between parents' knowledge about clubfoot and its treatment and their compliance with the treatment regimen.

5.6 Barriers to compliance

The third objective of this study was to identify barriers parents encountered in attending regular treatment appointments at the Talipes Clinics. When planning for rehabilitation services especially for children with physical impairments in many developing countries, it is usually taken for granted that all affected children and their caregivers will attend these rehabilitation services. However, in reality, not all children requiring evaluation and treatment do attend (Whitworth, Pickering, Mulwany, Ruberantwari, Dolin and Johnson, 1999). In addition, even those parents who do attend experience a number of barriers,

which are poorly understood by the rehabilitation care providers, and, if not addressed, could affect the effective utilization of rehabilitation services by the communities.

In this study, parents reported a number of difficulties they met in complying with the treatment regimen. These include financial difficulties, a lengthy distance from home to the hospital, bad experience of communication with the clinician, lack of family support and lengthy waiting time at the clinics. However, most parents reported bad experience of communication with the clinician and financial constraints to meet transport costs as potential difficulties they encountered in complying with the clubfoot treatment regimen.

5.6.1 Parents' experience of communication with the clinician

Research has shown that relationships between the health care provider and patient or caregiver determine the patient/caregivers behaviour during treatment (Van Wieringen, Harmsen and Bruijnzeels (2002). Good relationships are said to be vital for mutual understanding and are strongly correlated with compliance to the prescribed treatment whereas, consultations without mutual understanding often result in dissatisfaction with the treatment and more often end in poor compliance with the prescribed therapy and defaulting on treatment appointments (Van Wieringen, et al, 2002). According to Irochu-Omare (2004), a good health provider-caregiver communication involves exchange of information and, requires the health provider to interpret explanations, define or clarify issues and procedures and also to be prepared prior to the actual explaining. It is said that if the treatment process is explained to patients or caregivers, they are more knowledgeable, have more positive beliefs about their treatment, feel more satisfied with care, and are more likely to comply with the treatment requirements.

In this study, 67% of parents (n=112) indicated that the clinician did not explain to the parents about clubfoot and its treatment at the time of diagnosis or during treatment. Similarly, (64%) of the parents reported that the clinician did not give them the chance to explain their problems. In addition, 60% of parents (n=100) indicated that the clinician did not give them sufficient information about the treatment. However, it was interesting to find that although most parents indicated that the clinician did not give them sufficient

information about treatment, 90% of parents (n=151) indicated that the clinician informed them to follow the prescribed treatment. This indicates that parents were only directed what to do but not involved in the treatment process, which indicates there was more of an authoritarian relationship rather than a partnership between the clinician and the parent. The difference between the two hospitals may be that clinicians in Mulago Hospital had heavier caseloads of patients to attend to per each clinic session compared to their counterparts in Mbarara Regional Referral Hospital.)

This may be attributed to the fact that due to high caseloads, clinicians had little time to listen to the problems of each parent, resulting in many clinicians limiting the amount of time they had to providing treatment and only discussing a few if any of treatment related issues with the parents. This provided little opportunity for parent to inform clinicians of their concerns about the treatment. On the other hand, this poor interaction between the clinician and the parent could have been the result of organizational factors where parents met different clinicians each treatment session and clinicians did not know what information was given by the previous clinician and what was needed or missing. However, it is also possible that providing explanations to parents about the treatment process was not part of the treatment practice at the Talipes Clinics of the two hospitals.

The study also found that parents who were given a chance to talk about their problems were more compliant with the treatment regimen than parents who were not given this opportunity. It is likely that parents wanted clinicians to understand some of the problems they encountered in complying with the treatment regimen so that the clinician could provide some solutions or advice on how to overcome these problems. It has been shown that the way in which patients/caregivers are treated by health providers during clinical encounters or consultations for instance; being listened to, having a rapport with the health provider, receipt of respect and supportive care, information exchange and partnership determines their satisfaction with the care, and, their adherence behaviours to the prescribed treatment regime (King, Tamzin, King and Rosenbaum, 2002). It can be argued that those parents who were given a chance to explain their problems to the

clinician were given some solutions to some of the problems they found in adhering to the treatment regime and felt more satisfied with the care.

Research has shown that good interaction and relationship between health providers and patients/caregivers motivates patients/caregivers to be more involved in the treatment process, to open up and disclose information about the treatment and often results in a high sense of commitment on their behalf to the ongoing treatment process (Gail, Bachner, Merrick, Flusser, Lubertzky et al, 2006). It has been shown that patients who receive a comprehensive explanation about the treatment process and who have open dialogue with their health providers are more likely to be satisfied with the care and adherent to the prescribed treatment (Malta, Peterson, Clair, Freitas and Bastos, 2005).

Conversely, patients who have poor interactions with their health providers and those who receive inadequate information and/or do not understand their health providers' prescription recommendations are unlikely to adhere to the required therapy. However, it is interesting to find that despite the poor communication and interaction between the parents and clinicians in this study, all these parents complied to the treatment regimen and this indicates how committed they were to the treatment process.

On the other hand, it is not known how this poor communication may have affected those parents who were not compliant with the treatment regimen. Further research is needed to explore the influence of poor communication among the non-compliant parents to compliance with the treatment regimen.

The results of this study are consistent with the findings of Guevara, Feudtner, Rome, Power et al (2005) in a qualitative study on fragmented care for minority children with attention-deficit/hyperactivity in USA. They found that despite their indication of poor interaction and communication with their health providers about the condition of their children, most parents reported that they complied with the treatment requirements.

On the contrary, a study by Murphy, Roberts, Hoffman, Malina and Lu (2003) on barriers and strategies to antiretroviral adherence in Los Angeles, USA found that only 32% of patients (n=81) consistently adhered to the prescribed treatment regimen despite most of

them reporting good interaction and communication with their health providers on issues concerning medications and the treatment. However, the current study found no significant association between parents' experience of communication with the clinician and compliance to the treatment regimen except that they listened to problems and this was associated with compliance. This therefore shows that despite most parents reporting poor interaction and inadequate communication with their clinicians as one of the problems they encountered, this did not affect their compliance with treatment. It could be argued that parents were satisfied with the results of treatment and that this overshadowed some of the other problems they encountered during treatment.

5.6.2 Travelling distance

It is reported that in developing countries the effect of distance on service use becomes stronger when combined with lack of transportation and poor roads, which contributes towards indirect costs of visits to health care facilities. As discussed in chapter four, parents who travelled short distances of nine miles and less were more compliant to the treatment regimen than those who travelled long distances. These results support the findings of Beardsley, Wish, Fitzelle, O'Grady and Arria (2003) in USA, who found that the distance travelled to the treatment centre, was associated significantly with treatment retention and completion. Clients who travelled less than one mile were much more likely to complete treatment as compared to clients who travelled greater distances. This indicates that as the economic costs of treatment attendance increases with distance, the ability diminishes for clients to stay in treatment longer (Beardsley et al, 2003).

This study included parents from the urban areas and rural areas. There are no outreach services for clubfoot treatment in Kampala and Mbarara districts to cater for children in the community who are unable to utilize treatment from the Talipes Clinics. The difficulties of lengthy and costly journeys to the hospitals could be alleviated if clubfoot services are extended to the community. In Uganda, transportation costs differ depending on the distance travelled and the area. Most roads within the city and town centres are easily accessible whereas those in the suburbs and rural areas are inaccessible especially in the rainy seasons. This raises the transportation costs from those areas to the urban

centres where these Talipes Clinics are located. It can be suggested that minimizing the geographic distance that parents must travel to the hospitals through use of community outreach clinics might reduce transportation costs and improve accessibility of clubfoot treatment and, adherence to the treatment regimen.

5.6.3 Transport costs

In establishing the cost of access to health care services, the important starting point is the distance from home to the nearest health care facility, which determines how much the patient will pay before accessing the health services (Hjortsberg and Mwikisa, 2002). In the present study, 82% of parents (n=137) indicated that they found it expensive to bring their children for plaster casting every week. This finding could be expected considering the fact that 56% of the parents that participated in the study were unemployed and of this, 38% were housewives who depended on their husbands for financial assistance to bring their children to hospital for treatment. However, this study did not investigate the income and employment status of the fathers or mothers of these children. Likewise, the employment status of the family was not investigated.

The results of this study are consistent with findings of Ellis, Gogel, Roman, Watson, Indyk et al (2006) in a study on adherence to short-term drug regimens in Kenya where it was found that over 65% of the parents (n=233) reported having complied with the prescribed treatment for their children but reported financial problems as one of the major barriers they encountered in adhering to the required treatment program.

The study found a significant association between compliance and transport costs indicating that parents who found transportation costs to hospital very expensive were more likely to attend irregularly for treatment than those who found transport cheaper. This result supports earlier findings by Kim, and Tellen (2004) in Korea where it was found that mothers who experienced costs as a burden for the child's dental care were less likely to follow up on the treatment at the dentist. Similarly, Kalter, Salgado, Moulton, Neito, Contreras et al (2003) in a study on factors constraining adherence to referral advice for severely ill children in Ecuador found that high transportation costs to

health centres were significant constraints that prevented mothers from completing a referral program and their retention in treatment.

Since most of these parents who attended the clinic were unemployed, it is likely that they were financially dependent on their spouses or relatives and, had no direct control over the financial resources that were required to meet transportation costs and other necessary expenses. For instance, if the spouse or relative who provides finances to the parent failed to raise money for transporting the child and mother to hospital, the mother had either to borrow the money to meet transport costs or cancel the treatment visit to the hospital.

Transportation to health care facilities can be problematic for patients and caregivers especially in developing countries with poor transportation systems and poor infrastructure. There is no direct transportation from the homes of most parents to the hospital. Therefore it is likely that most parents used more than one mode of transport to reach the hospital and return home, apart from the very few who use private transport. For instance, in Uganda, patients/caregivers use motorcycle taxi or walk from home to the nearest taxi stage to have a taxi to hospital. This mode of transport would have increased the transportation costs, affecting most parents. These costs could be minimized if the treatment services for clubfoot are extended to the communities.

5.6.4 Waiting time

Although most parents did not report it as a major barrier to adherence to the treatment requirement, it is important to discuss the duration of waiting time for treatment at the Talipes Clinics of the two hospitals. In this study, 81% of parents waited for two or more hours for treatment. This is a very long a period to wait for treatment for children who easily tire and get hungry after an excessive wait and, for the mothers who have other responsibilities at home including caring for other children. This long wait could be due to the heavy case loads these clinics experience as these hospitals are the only public health facilities in the districts which offer treatment of clubfoot at no cost under special care of experts. It is possible that decentralizing treatment services for clubfoot could eliminate many of these barriers parents experience including the long hours parents have

to wait to access the services at these hospitals that is, taking these services from hospitals to the community (Konde-Lule et al, 2005).

5.6.5 Family support

It has been shown that family support provided by immediate family members working closely together directly affects the health of parents/caregivers and their behaviours. The study found a significant association between physical and financial support and compliance with the treatment regimen. This indicates that parents who had someone at home to take care of other children and those who had someone to provide finances to bring the child to hospital were more likely to attend regularly for treatment. These results correlate with findings of Kruse, Rohland and Wu (2002) in USA who found that receipt of family financial support among mothers was associated significantly with adherence to scheduled treatment regimens for their children. It is likely that the physical support received from family members relieved these mothers of strain and the burden of domestic responsibilities and care whereas the financial support enabled them to navigate easily through the complex transport system to the hospital.

It could be argued therefore that mothers who had neither kind of support not only found it hard to balance domestic responsibilities with the treatment requirements, but also could not afford the necessary costs, which resulted in poor compliance with the treatment regime.

5.7 Summary

The discussion focused on the major findings of the study in respect to the objectives of the study. The findings show that the majority of parents in the study were compliant with clubfoot treatment regimen of bringing the child for plaster cast change on consecutive weeks for 5 weeks. The study found that parents had poor knowledge of clubfoot before diagnosis but learnt more as they attended consecutive treatments of their children. Similarly, they indicated poor interpersonal relationships with the clinicians in addition to inadequate explanation of treatment procedures to parents. The study demonstrated significant associations between compliance of parents to treatment and some of the barriers parents encountered which included transport costs, family support and travelling distance. Transport costs and poor interaction between parents and

clinicians were found to be major barriers parents encountered during the utilization of services at the Talipes Clinics. This study provides information on the factors that might influence compliance of parents to their children's treatment and the difficulties they encounter in attending regular treatment appointments at the Talipes Clinics of Mbarara Regional Referral Hospital and Mulago Hospital that may act as barriers to attendance.

The limitations of the study, conclusions and recommendations follow in the next chapter.



CHAPTER SIX

SUMMARY, CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

6.1 Summary

The aim of the study was to investigate barriers to treatment attendance parents of children with clubfoot encounter in complying with clubfoot treatment during the plaster casting stage at Mbarara Regional Referral Hospital and Mulago Hospital. However, in order to attain this aim, the study determined: (i) parents' knowledge of clubfoot and its treatment; (ii) parents' roles during the plaster-casting stage of clubfoot treatment; (iii) the difficulties parents experienced in attending all treatment appointments; (iv) the associations between compliance to treatment and parent's knowledge about clubfoot, parents' experience of communication with the clinician and the difficulties parents experienced in attending all treatment appointments.

The study reviewed the literature on the incidence of clubfoot, causes of clubfoot, patho-anatomy and management of clubfoot, compliance/adherence to treatment and the consequences of not adhering to the treatment requirements, and, finally, the barriers parents encounter in following the treatment regimen.

A cross-sectional study design using a quantitative research method was selected for the study. The study population were parents/caretakers of children with clubfoot. The study sample included 167 male and female parents of children with clubfoot aged between 0-7 months. They were recruited from the Talipes Clinics of Mbarara Regional Referral Hospital and Mulago Hospital in Uganda. The study sample included the total study population. A structured questionnaire was used to collect data on: the parents' demography; number of treatment sessions attended; knowledge about clubfoot and its treatment; communication between clinician and parent during treatment; parent's role in the treatment of clubfoot; and the barriers parents encountered in attending regular treatment appointments.

The study employed descriptive and inferential statistics to analyze the data. The results showed that at the time at which the interview took place, 90% of parents who were attending the clinic, were compliant with the treatment requirements. Sixty seven percent of the parents lacked knowledge on clubfoot and its treatment although all parents knew of their role in the treatment. Despite the inadequate knowledge about clubfoot, 74% of parents knew the consequences of not following the treatment regimen. In addition, 67% of parents reported poor interaction with the clinicians regarding communication about the treatment process. The commonly identified difficulties parents encountered in attending treatment appointments included: financial constraints to meet transportation costs; bad experience of communication with the clinicians during treatment; and lengthy travelling distance.

6.2 Conclusion

From the results of this study, it can be seen that most parents who were attending the clinics at the time of the study were compliant. However, the majority of parents had poor knowledge and lacked information on clubfoot and its treatment, and were concerned with some aspects of treatment, in particular communication with the clinician regarding explanation of the treatment process. On the other hand, despite their inadequate knowledge on clubfoot and the treatment process, all parents knew of their role in clubfoot treatment, and most of them knew of the consequences of not adhering to the treatment regimen. In addition, the study identified some difficulties parents experienced in adhering to the required treatment program. These may have been barriers to attendance for other parents. These include financial constraints to meet transportation costs, travelling distance and inadequate parent-clinician communication.

6.3 Recommendations

The results of the study will be useful in improving service delivery of clubfoot at the Talipes Clinics of the two hospitals. In addition, the results will be useful in developing effective interventions aimed at enhancing utilization of services and compliance to the treatment regimen at the clinics. These results can be used by the hospital management to identify gaps in the delivery of health care services among health providers in the

hospital, so that interventions are sought to improve the health care delivery, for instance improving the communication skills of health providers through refresher courses.

Considering the results of this study, and the difficulties parents experienced in attending to all treatment appointments at the Talipes Clinics of Mbarara Hospital and Mulago Hospital, the following recommendations are made:

6.3.1 There is need for a health education program for parents at the Talipes Clinics of the two hospitals. This will increase awareness among parents about clubfoot and the treatment process. This can be implemented through use of pamphlets printed in local languages with good illustrations of the deformity and the treatment stages. Conversely, health education talks can be provided for parents as they wait for treatment in the waiting room. These talks can be conducted by the clinician, nurse or a medical educator. This can be an effective strategy of providing information to parents, as it requires few resources.

6.3.2 Although the clinicians working at the Talipes Clinics may know the importance of good communication, they may be lacking the skills of communicating information regarding clubfoot and the treatment process to parents. Therefore, there is great need for all clinicians at the Talipes Clinics of the two hospitals to undergo special training in communication and interpersonal skills and strategies. These can be organised in the form of workshops or seminars that can be held regularly so that clinicians are reminded of this essential requirement of care.

6.3.3 The researcher suggests that all treatment sessions of plaster casting for a particular patient should be done by the same clinician so that a parents' behaviour during treatment can be followed easily throughout the whole treatment session. This will provide an opportunity for a one-to-one interaction of the clinician with parent for a longer period of time and will provide chance for the clinician to help the family to cope with the prolonged treatment regimen.

6.3.4 The school of physiotherapy, school of orthopaedic clinical officers and the medical school at Mulago Hospital and Mbarara Regional Referral Hospital need to put emphasis on teaching communication skills of listening and explaining medical issues and procedures to their students so that graduates from these institutions can meet patients and parents' expectations regarding information provision.

6.3.5 There is need to decentralise services from the main hospitals to the health centres in the communities that are accessible to most patients/parents. This can be implemented through outreach clinics in communities that are located far way from the referral hospitals. This would shorten the travelling distance for parents, increase the accessibility of these services to the very poor that are unable to meet transportation costs and would be an effective strategy of taking services near the people.

6.3.6 The researcher also recommends that more research that involves both qualitative and quantitative approaches be done on the same topic at other referral hospitals to assess the rate of compliance of parents and the difficulties they go through in these areas. This would capture data and views of parents in different settings, which could be used to develop programs that could improve the treatment of clubfoot in Uganda. In addition, a similar study with a larger sample from all referral hospitals should be carried out for comparison, as the results of this study cannot be generalised since the study was done in only two urban referral hospitals. Results from comparative studies would capture data on the treatment needs of parents and barriers that influence treatment in the whole country.

6.3.7 There is need to increase the number of human resources in referral hospitals especially those correcting clubfoot to prevent shortages in public hospitals. This will make it easy for conducting outreach clinics in the community and, would give parents of children with clubfoot easy access to rehabilitation services for their children.

6.3.8 Interventions used in clubfoot correction need to be tailored to individual parents and families based on their unique circumstances, barriers and resources as revealed by

assessing the parent. This assessment can be done by obtaining information from parents through routine interviews on the barriers they encounter in the process of adhering to the treatment requirements and the information collected can be used to problem-solve with the parent on ways to overcome these specific barriers. These assessments should also take place periodically so as to monitor changes in parental compliance over the course of their involvement with the treatment and for the clinicians to know when and where to target intervention.

6.4 Limitations of the study.

6.4.1 The data collected was only from the parents who brought their children for treatment. There was no data on parents who were not attending the clinics, as it was difficult to locate them. Parents who did not attend may have experienced more barriers than parents who were attending the clinics. Future research should attempt to track down parents who do not attend to the treatment appointments at the clinics as required and identify the barriers they encounter.

6.4.2 This study was confined to one urban and one semi-rural setting. The findings may not be representative of all parents and their experiences in other settings for instance those in very rural settings. Thus the study results may not be generalised except to similar settings.

6.4.3 The method of data collection that was used (reading of questions from the questionnaire to the parent and the researcher completing the questionnaire with responses that were given) as requested by the parents versus self-administered questionnaires was cumbersome and subject to bias. This may have affected the responses parents gave. Similarly, this method affected the sample size in that fewer parents were interviewed compared to if parents had completed the questionnaires themselves.

6.4.4 The use of selection criteria meant that a subgroup of parents of children with clubfoot above seven months of age, plus those who had completed a course of plaster casting regimen, but because of poor correction were put on another course of plaster

casting regimen, were excluded from the study, of whom a few were still undergoing plaster casting treatment and experienced similar or even extra difficulties in adhering to the treatment requirements. This selection criterion was included because children with clubfoot above seven months of age do not respond to the use of the plaster-casting regimen. These often undergo surgical correction.

6.4.5 The findings of this study are based on a convenience sample of parents who brought their children for treatment at the Talipes Clinics. Thus they might not be representative of other parents who have children with clubfoot undergoing similar treatment in other settings.

6.4.6 The cross-sectional descriptive survey research design using a sample of convenience that was used could not capture all the relevant data on the compliance behaviours of parents during the plaster casting stage of treatment. In addition, the selection of a two months time period for the assessment of compliance was based on the time the researcher had to collect the required data and also on the financial constraints. It is possible that selection of a longer time period for example six months in which to measure compliance would give a different set of findings. Therefore a longitudinal study to monitor how parents comply with the treatment throughout the five weeks of plaster cast treatment and determine how compliance might change over time would be most appropriate for this study. In addition, the study design did not allow the researcher to capture data on the attitudes of parents towards adhering to the treatment requirements and the reasons why some were compliant and others were not.

6.4.7 The researcher was not able to locate a questionnaire that met the specific needs of this study. Therefore the research instrument used was not a standardised questionnaire. The researcher relied on face and content validity of the instrument after seeking expert opinion from a research expert. Therefore the instrument needs to be piloted to parents in other settings for instance rural settings to investigate whether the instrument will capture similar responses. In addition, research is needed to develop standardised tools to assess compliance across diverse study populations in different research settings.

However inspite of these limitations, the researcher believes that the current study sheds light on some of the factors that influence compliance by parents during the utilisation of services. Therefore rehabilitation care providers can understand the nature and severity of these influences and how they affect compliance or adherence to treatment so that solutions can be minimised for how they can be minimised or be overcome.



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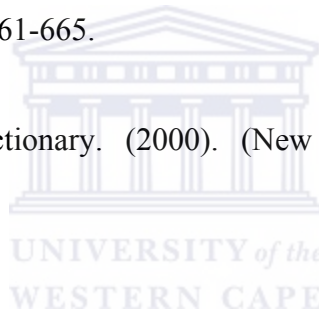
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APPENDIX 1

UNIVERSITY OF THE WESTERN CAPE (SOUTH AFRICA) DEPARTMENT OF PHYSIOTHERAPY

A Questionnaire on factors affecting compliance of parents of children with clubfoot deformity between the ages of (0-7months) to rehabilitation treatment during the casting stage in Mbarara regional referral hospital and Mulago national referral hospital in Uganda.

Dear parent;

My name is Kazibwe Herman, a Master's student of Physiotherapy enrolled at the University of the Western Cape (UWC) in South Africa. I am conducting a research survey as part of the requirements for Master's degree in Physiotherapy. The title of my study is "**Factors affecting compliance of parents of children with clubfoot deformity to rehabilitation treatment in Uganda**". The results of the study will be used as a guide to plan treatment interventions for improving rehabilitation services of children with clubfoot. I kindly request for your participation in this study by completing the questionnaire according to the statements given in the questionnaire. The participation is voluntarily and the information given will be confidential. If you do not wish to participate in the study, your child's treatment will in no way be affected.

Please do NOT write your name on this questionnaire.

Its is hoped that the information you will give in this study will be helpful in planning for improving rehabilitation services for children with clubfoot in government hospitals in Uganda.

QUESTIONNAIRE.

Instructions: please select one response by using a tick in the box of your choice.

1. Person who brings child to hospital. 1. Fat 2. other 3.
Grandmother 4. Others specify -----

2. Date of birth of parent. Date ----- Month----- Year -----

3. Date of birth of the child Date ----- Month ----- Year -----

4. What is your current marital status?

1. Single 2. Married 3. Divorced 4. Widowed

5. What is your employment status?

1. Employed	<input type="checkbox"/>
2. Self employed	<input type="checkbox"/>
3. Unemployed	<input type="checkbox"/>
4. Housewife	<input type="checkbox"/>
5. Retired	<input type="checkbox"/>
6. Student	<input type="checkbox"/>

6. Have you ever attended school? Yes No

7. If yes, what is the highest education level obtained?

1. University	<input type="checkbox"/>
2. High school	<input type="checkbox"/>
3. Secondary	<input type="checkbox"/>
4. Primary	<input type="checkbox"/>
5. Did not attend	<input type="checkbox"/>
6. Don't know	<input type="checkbox"/>

8. Name of the hospital where you attend treatment.

1. Mbarara hospital	
2. Mulago hospital	

9. When was your first visit to this clinic? Date ----- Month ----- Year -----

10. Who referred you to this clinic?

1. Medical personnel	
2. Traditional birth attendant	
3. Friend	
4. Self referral	

5. Others -----

11. Do you attend to treatment regularly? Yes No

If yes, how often?

1. Daily	
2. Weekly	
3. Every after 2 weeks	
4. Every after 3 weeks	
5. Every after 1 month	

12. Did you know what clubfoot deformity was before your child was diagnosed?

Yes No

13. At the time of your diagnosis, did the clinician explain to you what club foot deformity was? Yes No

14. Were you told by the clinician to follow the prescribed treatment program?

Yes No

15. Did you understand why you had to follow the prescribed treatment?

Yes No

16. Were you given any written reminder of the attendance dates to this clinic?

Yes No

17. How many times have you attended to this clinic in the last 1-month? -----

18. What difficulties do you have in following the prescribed treatment?

1. Do you understand why you should attend treatment every week?	Yes	No
2. Is it very expensive to attend to treatment every week?	Yes	No
3. Do you have the time to attend to treatment every week?	Yes	No
4. Do you have anyone to leave other children with at home?	Yes	No
5. Is your home very far from the hospital to make it every week?	Yes	No

6. Other -----

19. For this visit, how long did you wait for treatment?

1. Less than 30 minutes	
2. Greater than 30 minutes	
3. Approximately 1 hour	
4. Approximately 2 hours	
5. Approximately 3 hours	
6. More than 3 hours	

20. Does this time affect your other programs of the day? -----

21. What time do you consider reasonable to wait for treatment? -----

For each of the following questions choose the appropriate answer by ticking in the appropriate box.

22. Does the clinician explain to you about the condition before carrying out casting of the baby? YES NO

23. Do you feel the clinician gives you enough information about the treatment? YES NO

24. Does the clinician give you chance to talk about your problems? Yes No

25. Are you satisfied with the treatment? Yes No

26. Is it necessary to attend to treatment as prescribed by the health professional? Yes No

For each of the following questions, tick only one answer of your choice

27. What do you think will happen if you do not attend to treatment as prescribed?

1. Child's foot/feet will turn in/become disfigured more than before	<input type="checkbox"/>
2. Child's foot/feet will correct themselves	<input type="checkbox"/>
3. Child's foot/feet will remain as they were before treatment	<input type="checkbox"/>
4. Don't know	<input type="checkbox"/>

28. Who provides you financial assistance to bring the child for treatment?

1. Child's father	<input type="checkbox"/>
2. Child's mother	<input type="checkbox"/>
3. Your mother or father	<input type="checkbox"/>
4. Your husband's mother or father	<input type="checkbox"/>

5. Friends	
6. Others	

29. How far is your home from the hospital? -----Miles

30. How much do you pay for your transport to hospital? ----- Shillings

31. What role do you as a parent play in the long-term treatment of clubfoot?

1. Attend regularly to the prescribed treatment Yes No

Don't know

2. Care for the plasters. Yes No Don't know

3. Ensure that child is worn with foot abduction braces all the time as required after plaster removal. Yes No Don't know

32. How are you supposed to care for the plaster cast?

1. Not to pour water on the plaster	Yes	No	Don't know
2. Prevent child from wetting plaster with urine	Yes	No	Don't know
3. Not to allow child to play with plaster on wet floor/ground	Yes	No	Don't know

33. Why do you think a plaster cast needs to be changed?

1. For inspection, stretching of the foot, and exercises	Yes	No	Don't know
2. To allow increase in the size of foot	Yes	No	Don't know
3. To maintain cleanliness of the foot	Yes	No	Don't know

Thank you for your time and God bless you.

APPENDIX 2

UNIVERSITY OF THE WESTERN CAPE (SOUTH AFRICA)

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DEPARTMENT OF PHYSIOTHERAPY

Okubuliliza kunsonga eziletera abazadde babaana abalina obulema bwe bigere obutatukiliza bujjanjabi bwabaana bano mu Uganda.

Ssebo/nyabo omuzadde

Amanya gange nze Kazibwe Herman nsomera mu Yunivasite ye Cape Town mu maserengeta ga Afirika. Okubuliriza kuno byebimu ku byetaago bya diguli ngyensomerera era ebinavaamu bijja kuyamba mu kulongoosa mumpeereza yobujjanjabi bwa baana bano mu Uganda. Osabibwa okwetaba mu kubuliliza kuno nga ojjuzza form eno. Okwetaba kwo mu kubuliliza kuno kwa kyeyagalire era buli nsonga yonna gyonowa ejja kutwalibwa nga yakyaama. Bwosalawo obutetaba mukubuliliza kuno tekujja kugootanya oba kusazaamu mu bujjanjabi bwomwaana wo mu kiliniki eno.

Osabibwa obutawandiika linnya lyo ku lupapula luno.

Londako ekituufu ku bino wamanga nga ogenda ogolola mukabokisi akateledwaawo.

Ani aleeta omwana mudwaliro? 1.Taata 2.Maama 3. Jjaja
4. Abalala

1. Ebiseera omuzadde bye yazalibwaako
Olunaku----- omwezi ----- omwaka -----
2. Ebiseera omwana bye yazalibwaako
olunaku ----- omwezi ----- omwaka -----
3. Embeera yamaka gyolimu: mufumbo simufumbo

5. Embeera yemirimo gyo (londamu kimu)

Okozesebwa	
Wekozesa	
Tolina mulimu	
Oli mukyala wawaka	
Wawumula	
Muyizi	

6. Wali osomyeko? Ye nedda

7. Bwoba wasomako, wakoma ku ddala ki?

Tendekero ekulu (yunivasite)	
Eddala elyewaggulu (Siniya 5 okutuuka S6)	
Eddala elyawakati (Siniya 1 okutuuka siniya 4)	
Eddala erisokerwako (Primary)	
Sisomangako	
Simanyi	

8. Di lwewasooka okujja mu kilinika eno?

Olunaku----- omwezi----- omwaka -----

9. Ani yakusindiika mu kilinika eno?

1. Musawo	
2. Muzalisa owomukyalo	
3. Mukwano gwo	
4. Gwe wereeta (wesalilawo)	
5. Abarara	

10. Omwana omutwala mudwaliro okufuna obujjanja buli kiseera? YE Nedda

Bwekiba kyekyo buli luvanyuma lwabanga ki?

1. Buli lunaku	
2. Buli wiiki	
3. Buli luvanyuma lwa wiiki biri	
4. Buli luvanyuma lwa wiiki satu	
5. Buli luvanyuma lwa mwezi	

11. Wali omanyi obulema bwebigere buno ngomwaana wo tanaba kujjanjabibwa oba

kukolwako? Ye nedda

12. Mukusooka okujjanjaba omwana obulwadde buno, omusawo yakunyonyola ebifa ku

obulwadde buno? Ye nedda

13. Wategezeebwa okugoberera obujjanjabi nga bwebwali buwandikidwa oba bulagidwa? YE Nedda

14. Omanyi lwaki walagibwa okugoberera enzijjanjaba eyo? Ye Nedda

15. Wawebwaayo akantu kona mubuwandiike akakujjukiza enaku zokufunilako obujjanjabi? Ye Nedda

16. Mirundi emeka gyoze okufuna obujjanjabi mu kilinika eno mu mwezi oguwedde? --

17. Buzibu ki bwosanga mukugoberera obujjanjabi buno?

1. Simanyi lwaki ntekedwa okujja buli luvanyuma lwa wiiki	
2. Kyabuseere okugenda okufuna obujjanjabi buli wiiki	
3. Sifuna budde oba biseera kugenda kufuna bujjanjabi obwo buli wiiki	
4. Sirina gwendekera baana waka okusobola okugenda okufuna obujjanjabi	
5. Ngyebeeru wala neddwaliro okusobola okufuna obujjanjabi obwabuli wiiki	

6. ensonga endala -----

18. Kumulundi guno omazeewo budde ki nga tonafuna bujjanjabi?

1. Wansi weddakika assatu	
2. Kisusse muddakika assatu	
3. Saawa nga emu	
4. Saawa nga biri	
5. Saawa nga satu	
6. Okussuka esaawa ssatu	

19. Obudde bwomazewano bulina engeri gyebugotanyiinzamu entekateka yo eyolunaku? -----

20. Budde ki bwolaba obwandigwanidde okulindirako obujjanjabi?

kubibuzo bino wamanga laga oba okiriza oba tokiriza nabyo nga ogenda ogolola mu kabokisi akalekedwaawo

21. Omusawo akunyonyola ekikyamu kumwana ono nga tanaba kukuwa bujjanjabi bwona? Ye Nedda

22. Olowooza omusawo akunyonyola bulungi ku nsonga ekwata kubujjanjabi buno? Ye Nedda

23. Omusawo akuwa omukisa okunyonyola obuzibu bwo? Ye Nedda

24. Oli mumativu nobujjanjabi obukuweebwa? Ye Nedda

25. Kyetagisa okufuna obujjanjabi ng omusawo bwakulagidde? Ye Nedda

Kubibuuzo bino wamanga golola ekyo kyolonzeewo nga kyekituufu.

26. Olowooza kiki ekiyinza okudirira singa togenda kufuna bujjanjabi bukulagidwa?

1. Ebigere byomwana bijja kwongera okugongobala	
2. Ebigere byomwana bijja kuterera byoka	
3. Ebigere byomwana bijja kusigala nga bwebyali nga tanafuna bujjanjabi	
4. Simanyi	

27. Ani akuwa obuyambi bwensimbi okutwala omwana okufuna obujjanjabi muddwaliro?

1. Kitaawe womwana	
2. Nyina womwana	
3. Kitaawo oba Nyoko (maamawo)	
4. Sezaala or Nazaala	
5. Mikwano gyo	
6. Abarara	

28. Buwanvuki obuliwo okuva ewuwo okutuuka ku ddwaliro?----- miles

29. Bisaleki byosasula kuntambula okugenda okufuna obujjanjabi muddwaliro?

----- shillings

30. Buvunanyizibwa ki omuzadde bwalina mukujjanjaba obulwadde buno?

1. Okujjumbira obujjanjabi buli budde obulagidwa	Ye	Nedda
2. okulabilira pulasita	Ye	Nedda
3. okulaba nti omwana ayambazibwa obugato bwekyuuma obudde bwonna nga bwekiragiddwa oluvanyuma lwokumujjako pulasita	Ye	Nedda

31. Otekedwa otya okulabirira pulasita eri kumwana?

1. Butagiyiwaako mazzi	
2. Okuziyizza omwana okugifukira	
3. Obutakiriza mwana alina pulasita kuzanyira wantu wabisi oba awali amazzi	
4. Simanyi	

32. Olowooza lwaki pulasita egwanidde okukyusibwa?

1. Okusobola okukebela wamu nokugolola ekigere saako nokukikyusa kyusa mu nyingo zaakyo	
2. Okusobozesa ekigere okugejja munkula yakyo	
3. Okukuuma ekigere nga kiyonjo	
4. Simanyi	

Webale nnyo olwobudde bwo bwotuwadde okujjuza form eno wamu nokwetaba mukunonyereza kuno.

APPENDIX 3

UNIVERSITY OF THE WESTERN CAPE

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DEPARTMENT OF PHYSIOTHERAPY

EKITONGORE EKIBUNGI

Orukarara rwebibuuzo ebikaturine nenshonga ezirikuzibira abazaire ba baana beine ebigyere bimugire kwikiriza kubigarura omubuteeka obwo biri kubungwa omu Uganda.

Sebo/Nyabo Omuzaire

Amaziina gangye ndi Herman Kazibwe, omwegi wa diguri yakabiri omubyokubunga, omutendekyero ekuru erya Western Cape omumashuma ga afrika. Nkabimwe aha byetago bya diiguri yangye yakabiri omukubunga ndiyo ninkora okucondooza/okwega. Omutwe gwo okwega oku/okucondooza oku ni:

Enshonga ezirikuzibira abazaire ba'baana beine bigyere bimugire (bikikami, birinke-enkoni) kwikiriza kubigarura omubuteeka obwo bari kubibunga omu Uganda.

Ebirarugye omukwega oku nibyeija kukoze sibwa nkeyokureberaho kutaho entekateka zokwongyera aha mutindo gwo kubunga ebigyere byabaana bikagaruka omubuteeka.

Ninkushaba nembabazi kwikiriza kwetaba omukucondooza oku/okwega oku obwo'rikugarukamu orukarara rwebibuuzo okurugirira aha bigambo ebiri omurukarara rwebibuuzo oru.

Okuza omukucondooza oku kiri aha bwawe, nozamu oyekundiire tihariho kukukaka kandi nokumanyisibwa okwo'rampereze nikuza kuguma kuri ekihama/okwomubonano. Waba otarikukunda kuza omukucondooza oku/okwega oku, tekirikwija kukuzibira omwaana waawe kutunga obujanjabi omumuringo gwona. Nakweshengyereza otahandiika eiziina ryawe aharukarara rwebibuuzo oru. Twine amatsiko ngu okumanyisibwa oku oratuhereze omukucondooza oku/okwega oku nikwija kuyamba aha ntekateka yokwongyera omutindo gwokugaruza busya obuhereza omukubunga abaana beine ebigyere bimugire omu marwariro ga gavumente.

ORUKARARA RWEBIBUZO

Ebiragiro: Torana ekigaru kwamu kimwe orikugorora omukabokisi

1. Ebiro byokuzarwa kwomuzaire: Ebiro ----- okwezi ----- omwaka -----

2. Ebiro byo'mwaana yazarirweho: Ebiro ----- okwezi ----- omwaka -----

3. Ori ki? Omushaja omukazi

4. Ebikwatiirine nobushwere oyemereire ota?

Omuhuuru Nyiineamaka Tukataana Efakaazi

5. Ebikwatiirine nemirimo oyemereire ota?

1	Nyine omurimo	
2	Ninyekozesa	
3	Tinyine murimo	
4	Ndi omukaazi wahaaka	
5	Nkahumura	
6	Ndi omwegi	

6. Okazaho omwishomero? Ego Ngaha

7. Kwerabe eri ego, okahiika aha rurengoki rwobwegyese?

1	Yunivasite	
2	Haaya	
3	Siniya	
4	Purayimare	
5	Tindagiriyo	
6	Tinkumanya	

8. Niryari obwo'banza kwija omwijanjabiiro eri?

Ebiro ----- okwezi ----- omwaka -----

9. Nooha owakwohereize omwijanjabiiro eri?

1	Owebyamagara (omushaho)	
2	Omuzarisakazi owekyaaaro	
3	Munywani wangye	
4	nkereta	
5	Omuringo ogundi	

10. Nokiira kujanjabwa? Ego Ngaha

Kwerabe eri ego, ninkemirundi engahi?

1	Buri eizooba	
2	Buri sande	

3	Buri bwanyiima yesande ishata	
4	Buri bwanyiima yokwezi kumwe	

11. Okaba nomanya eki bigyere bimugire nke nkoni kyabiire nikimanyisa obu abashaho

babiire batakahirize ngukwo omwaana aine ekigyere kimugire?

Ego Ngaha

12. Omubwire obu wamanyiremu oburwire, omushaho akakushoborera eki ebigyere bimugire nikenkoni kirikumanyisa?

Ego Ngaha

13. Bakakushoborera kukuratira entwaaza yobujanjabi eibakuhandikire?

Ego Ngaha

14. Oketegyereza, aha bwenki okaba oine kukuratira obujanjabi obu bakuheire?

Ego Ngaha

15. Bakakuhereza ekihandiiko kyokukwijutsya amazooba gokwija aha irwariro eri?

Ego Ngaha

16. Nemirundi engahi eyoyizire omwirwariro eri, omukwezi okuhweire? -----

17. Niburemeziki obuwatungiire omukukuratiira obujanjabi obu waheirwe?

1	Tinkumanya ahabwenki nyine kwija burisande	Ego	ngaha
2	Nekyobusere kwija burisande	Ego	ngaha
3	Tinyiine bwire bwokuguma nenyija burisande	Ego	ngaha
4	Tinyiine wokusigira abandi baana omuka	Ego	ngaha
5	Eka yangye erihare neirwariiro	Ego	ngaha
6	Obundi buremezi	Ego	ngaha

18. obuweija aha irwariro, kikakutwarira obwiire bukwenganaki kutegyereza obujanjabi?

1	Edakiika ziri ahansi yamakumi ashata (30 min)	
2	Edakiika zirengiire omwiimakumi ashata (30 min)	
3	Eshaaha emwe	
4	Nke'shaha ishata (3)	
5	Nkeshaha ibiri (2)	
6	Eshaha ezirengire omuri ishata (3)	

19. Eshaha ezi, zeine okuziri kuteganisa entebekanisa zawe zeizooba eryo? -----
-
20. Nishaha ziri kwinganaki, ezorikutekateka kuba nizimara, kutegyererezamu obujanjabi? -----

Buri kimwe aha bibuzo ebirikukurataho, gamba oba noikiriza neinga otarikwikiriza obwo ori kucebera akabokisi akahikire

21. Omushaho nakushoborera ekishobire (oburwire) atakakuheire obujanjabi bwona? Ego Ngaha
22. Nogira ngu omushaho nakuhereza okumanyisibwa aha bujanjabi oburikumara? Ego Ngaha
23. Omaziirwe nobujanjabi obwori kuhebwa? Ego Ngaha
24. Omushaho nakuhereza omugisha gwokugamba aha buremezi bwawe? Ego Ngaha
25. Nikyetengyesa kwija kutunga obujanjabi nkoku omushaho ari kuba akugambiire/akuhandiikire? Ego Ngaha

Ahabwebibuuzo ebiirikukurataho, kyebera ekigarukwamu kimwe

26. Notekateka ngu hakabaho ki waba oteizire kutunga obujanjabi nkoku omushaho ari kuba akugambiire/akuhandiikire?

1	Ekigyere/ebigyere byomwana nikija kweyongyera kukikama	
2	Ekigyere/ebigyere byo'mwana nibyeija kwegorora byonka	
3	Ebigyere/ekigyere kyo'mwana nikiguma nikokyabaire kiri atakatungire bujanjabi	
4	tinkumanya	

27. Noha orikukuhereza obuyambi bwa sente?

1	Ishe womwaana	
2	Nyina womwaana	
3	Maawe/Taata	
4	Ishe/Nyina baaro	
5	Abanyamukago	
6	Abandi bantu	

28. Okuruga owawe kuhika aha irwariro nihenganaki? Milo -----
 29. Orugyendo rwokwija aha irwariro norushashurira shillings zingahi? -----

30. Nimurumoki ogu omuzeire arikukora omu kujanjaba abaana beine ebigyere bimugire?

a). Nakozeza obujanjabi obumuheirwe? Ego Ngaha Tinkumanya

b). Nareberera ebibakuba bashembeise omwana (plaster)
 Ego Ngaha Tinkumanya

c). Kuse ngu buzima omwana yaguma ajweire ebikukwata ekigyere nikokukiri kwetengyesa obwiire bwona baheza kwihamu pulasita
 Ego Ngaha Tinkumanya

31. Oshemereirwe kureberera ota pulasita (plaster)?

1	Otashuka amaizzi aha purasita	
2	Kutanga omwaana kusheshera purasita (plaster)	
3	Kuteikiriza omwaana kuzanira ahari amaizzi	
4	Tinkumanya	

32. Ahabwenki notekateka ngu purasita (plaster) neyentenga kuhindurwa?

1	Kuchebera nokworoberwa kugorora ekigyere kyomwaana	
2	Kwenda ngu ekigyere kyeyongyera aha size	
3	Kwenda ngu ekigyere kigume kire ekiyonjo	
4	Tinkumanya	

Webare munonga Ruhanga akuhe omugisha