

**FACTORS INFLUENCING CEREBRAL PALSY CAREGIVERS' ADHERENCE TO  
OCCUPATIONAL THERAPY IN USAIN GISHU COUNTY: A CASE OF MOI  
TEACHING AND REFERRAL HOSPITAL**

**By**

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**DECLARATION**

I hereby declare that this is my original work and has never been presented for any academic award in any University.

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## **DEDICATION**

I dedicate this research to all Cerebral Palsy Patients and all the members of the Rehabilitation team who work tirelessly to ensure that Cerebral Palsy Children and their families have improved quality of life.

## **ACKNOWLEDGEMENT**

I take this opportunity to thank all the people who have made a contribution in my academic life so far. I would like to extend my gratitude to everyone who has contributed in one way or another in the development of this research mostly to the University of Nairobi for giving me the opportunity to study this course. I extend my sincere gratitude and appreciation to my supervisor Dr. Anne Assey for her guidance, support and assistance in this research and for her timely response to my work encouragement for better work.

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## **ABSTRACT**

Cerebral palsy is regarded as one of the leading cause of childhood disability worldwide. If poorly managed it can result in negative health outcomes, permanant disabilities increased healthcare costs. Little is known about the factors causing cerebral palsy nonadherence to occupational therapy intervention in UasinGishu County. The aim of this study was to identify factors influencing caregivers' adherence to prescribed occupational therapy intervention in Uasin Gishu County and suggest strategies for reducing their impact. The objectives of the study were: to examine the effect of travelling distance on adherence to occupational therapy intervention; to find out the influence of communication between clinician and the caregivers on adherence to occupational therapy intervention;to examine the impact

of social/economic support on adherence to occupational therapy intervention; the effect of waiting time on adherence to therapeutic intervention; the effects of parents knowledge of disease on adherence and importance of treatment. The purpose of the study was to identify factors influencing caregivers adherence to occupational therapy in Uasin Gishu County. The study employed qualitative design and purposive sampling technique in sample and gathering data. The target population were all the cerebral palsy caregivers bringing their children for occupational therapy at Moi Teaching and Referral Hospital, and all the occupational therapists working in occupational therapy outpatient department as key informants. The research instruments used to collect data included interview schedule guide, focus group discussions and structured questionnaires for the key informants. With the guide of the Health Belief Model (HBM) conceptual framework. Data collected was analyzed using thematic content analysis and descriptive statistics and frequency distribution tables and Percentages were used to demonstrate the results. The study findings were realized and conclusion and recommendation were made, which may aid in improving treatment of cerebral palsy patients. Results indicated that all parents understood their role in the treatment of cerebral palsy and consequences of not following the treatment regime. The factors that affect parents attending regular occupational therapy appointments include: travelling distance and high cost of treatment; poor social/family support and, poor knowledge of cerebral palsy and its treatment. The respondent reported that they did not have any problems with waiting time and interaction with the clinicians. Conclusion- there is need for the government to increase awareness through sensitization on, cerebral palsy and its treatment among the parents and caregivers. There is need to decentralize cerebral palsy services away from referral hospitals to the people in the community through outreach programs.

## INTRODUCTION

### 1.1 Background of the Study

Cerebral palsy is an umbrella term encompassing a group of non-progressive, noncontagious neurological conditions that cause physical and cognitive disability in human development, in which functional performance, participation, movement, strength, posture, muscle tone, sensation, vision, perception, communication, and behavior can be affected. Cerebral palsy is caused by damage to the motor control and cognitive centers of the developing brain and can occur during pregnancy (approximately 75 percent), during childbirth (approximately 5 percent) or after birth (approximately 20 percent) (ThorngrenJerneck & Herbst, 2006).

Due to the challenging clinical presentation of children with cerebral palsy, Occupational Therapy practitioners, physical therapy practitioners, and other healthcare providers are challenged to utilize the best available evidence to optimize functional outcomes for these children. The effects of cerebral palsy on the child are devastating both to the caregiver and the child. It is the major cause of disability in childhood today, with most of the affected countries being those with low socioeconomic development. There are a variety of rehabilitation options for [children with cerebral palsy](#). This are dependent on which [type of cerebral palsy](#) the

patient has. All of the rehabilitations, however, usually center on developing a few key areas of improvement including physical movement and coordination, speech. Ongoing treatments and options are available that could make life for the cerebral palsy child and caregiver better. Most rehabilitation and treatments use combination of , occupational and speech therapy, drugs, and even. Cerebral palsy rehabilitation will invariably involve long-term physical therapy.

Rehabilitation services are internationally recognized as one of the key components of health care (WHO, 1995). Presently only 2% out of one million people with disability in Developing countries receive rehabilitation services (MOH, 2003a). This is therapeutic intervention aimed at enhancing or improving lost function as a result of disease or traumatic injury. Cerebral Palsy requires long term rehabilitation depending on the severity of the child has been affected. According to, Bhatia and Joseph (2001).

Occupational Therapists are essentially members of the rehabilitative team in cerebral palsy treatment both in developing and developed countries (Shack and Eastwood, 2006). These are services that parents/caregivers of children with cerebral palsy seek to alleviate the effects of disability on their children. Occupational Therapy intervention for children with cerebral palsy aims to make

the child as independent as possible in the Activities of Daily Living(ADL) e.g. toileting, dressing, eating and bathing and also communication.

Occupational Therapists provide supportive devices like splints and braces for the correction of deformity and also for aiding in mobility. Occupation Therapy services are offered to patient with caregiver playing a great role because the child has to be given treatment frequently including in the home environment which also requires therapists to adapt the home environment and equipment, like feeders and seats to suit the child.

Parents of children with cerebral palsy need to be enlightened on the importance of care and treatment of their children in order to participate effectively in their treatment. Occupational Therapists need not only treat the child but also educate the parent/caregivers on the diagnosis, services and also the expected outcome. During rehabilitation of cerebral palsy it requires that the patient attend therapy for long periods and consistently for better outcome.

Consistent attendance and adherence is a primary determinant of the effectiveness of treatment (WHO, 2002., Cramer JA, 1998). Poor adherence results in poor outcome, for example a study by (Waeber B, Burrier M, and Brunner HR., 2000) found that there was poor control of blood pressure due to poor adherence. Adherence with treatment is an important factor which can influence the outcome



of that treatment. Poor adherence to treatment has been identified in many healthcare disciplines including occupational therapy ([Vasey, 1990](#); [Friedrich et al., 1998](#); [Campbell et al., 2001](#)).

The extent of non-adherence with occupational therapy treatment is not clear. Without adherence the therapeutic goals cannot be achieved resulting in poor outcome and poor quality of life (Cameroon, 1996). Inadequate Information regarding reasons for compliance or non-adherence to treatment can make it difficult to weigh the benefit of prescribing treatment to the patients (Modi, Himm Geller, Wagner, Quittner, 2006). It is therefore important to understand how parents/caregivers manage their children treatment and the potential challenges encountered during the attendance to Occupational Therapy treatment. It is important to identify factors that may positively or negatively influence parents/caregivers attendance to the clinics.

According to the United Cerebral Palsy (UCP) Foundation, approximately 764,000 children and adults in the United States are living with one or more symptoms of cerebral palsy. In other developed countries the number can be as high as one child in every 300. A study done in Chicago U.S. identified, funding for therapy services as a key challenge encountered by caregivers of cerebral palsy children when seeking treatment (Hinchcliff, 2003). Other challenges included

environmental problems in accessing therapy, for example build environment, infrastructure, institutional challenges, attitudinal and stigma that prevented them from participating fully in therapy and rehabilitation.

A study in Canada identified adherence to rehabilitation services as a challenge in Ontario, which was based on eligibility, or unavailability of funding, rather than on demand, Landry M.D (2004). A research published by the Drexel University in Washington DC found that family financial hardships, the child's age, and management care practices and health insurance plans, to be the primary factors contributing to problems related to adherence to therapy services for children with special healthcare needs O'Neal Margret E (2003).

A study done in Saudi Arabia identified organizational factors as contributing to treatment adherence. This included time spent with the doctor, continuity of care by the doctor, communication style, as an important socio-demographic variable (Albaz RS, 1997:25:5-8). On the other hand a study done at a pediatrics clinic in Nigeria, found that lack of adequate facilities for proper rehabilitation of children with neurological disorders appears to be the main cause for the high default-rate from follow-up. The study found that more children with cerebral palsy tend to default from follow-up visits compared to children with seizures because proper choice of anticonvulsants, meaningful control of seizures

can be achieved in children with seizure disorder, thereby encouraging parents to continue follow-up visits (Wammanda RD, Onalo R, Adam SJ, 2007: 6(2):73-75). Other studies have attributed increased defaulter rate to poor socioeconomic status, poverty, illiteracy, low level of education, unemployment, lack of effective social support networks, unstable living conditions long distance from treatment Centre, high cost of transport high cost of medication, cultural beliefs about the illness and family dysfunctions.

In Kenya little published literature on adherence to occupational therapy is available and therefore causes of constant non-adherence is not well understood. Occupational Therapy services are offered in the National and county hospital as well as all the county hospitals and some sub-county government and private hospitals in Kenya. The study set out to identify factors influencing cerebral palsy parents/caregiver's adherence to occupational therapy services at Moi Teaching and Referral Hospital in Usain Gishu County. Occupational Therapy Treatment programs are designed to help patients realize improved balance, interpret, appropriately perceive, and respond to their environment, live as independently as possible and achieve the best possible of life. From the hospital records at Moi Teaching and Referral Hospital, there are approximately 300 cerebral palsy patients annually with 100 being new patients and 50% of this number abandoning treatment before they are fully rehabilitated. The aim of this study therefor was to

find out the factors influencing cerebral palsy parents/caregivers adherence to occupational therapy.

Occupational Therapy services are offered at Moi Teaching and Referral Hospital for both in-patients and the out-patients. Patients who receive occupational therapy services include patients with mental health problems, paediatric patients with delayed developmental milestones including cerebral palsy. According to the hospital records most of the children with cerebral palsy are referred by the doctors to occupational therapy from the maternity wards, the general paediatric wards, pediatrics outpatient clinics, and from the surrounding hospitals including private clinics. Patients with cerebral palsy are also referred from the surrounding county hospitals of Baringo, Nandi County, Keiyo Marakwet and parts of Kakamega and Bungoma counties. The hospital records indicate that averages of 300 patients with cerebral palsy are treated per year.

### **1.2 Statement of the Problem.**

Medications that are prescribed following consultation with a medical professional are usually dispensed with an expectation of close to perfect adherence. Such expectations entail consistent adherence to the treatment regimen over time (World Health Organization, 2003). Patient non-adherence may therefore have severe implications for the control of symptoms, recovery time, and quality of

life. Clinical records at the Occupational Therapy Outpatient Department, at Moi Teaching and Referral Hospital, UasinGishu County Kenya, indicate that there is a rising incidence of Cerebral Palsy patients' default on prescribed occupational therapy treatment. Records of 2011 indicate that defaulter rate was at 34 %, in 2012 it was at 40 % and 2013 it was 42%. Default on rehabilitation program may be as result of a number of factors which indicate that gaps exist in the provision of rehabilitation services. Cerebral palsy is a chronic condition which requires long term management and therefore is important to identify the factors influencing cerebral palsy caregivers' adherence to occupational therapy intervention which will assist policy makers on how best to align the services for the benefit of children with cerebral palsy.

### **1.3 Purpose of the Study**

The purpose of this study was to investigate factors influencing cerebral palsy parents/caregivers' adherence to prescribed occupational therapy intervention at Moi Teaching and Referral Hospital, Usain Gishu County, Kenya.

### **1.4 Research Objectives**

The objectives of this study included the following;

- 1) To examine the effects of travelling distance on adherence to occupational therapy intervention

- 2) To find out the influence of communication between clinician and clients on adherence to occupational therapy intervention;
- 3) To examine the impact of social/economic support on adherence to occupational therapy intervention;
- 4) To assess the effect of waiting time on adherence to occupational therapy;
- 5) To find out the effects of parent's knowledge of cerebral palsy on adherence to occupational therapy intervention.

### **1.5 Research Questions**

- i. What is the effect of travelling distance on adherence to occupational therapy intervention?
- ii. What is the influence of communication between clinician and clients on adherence to occupational therapy intervention?
- iii. What is the impact of social/economic support on adherence to occupational therapy intervention?
- iv. What are the effects of waiting time on adherence to occupational

therapy intervention?

- v. What are the effects of parent's knowledge of disease on adherence to

occupational therapy intervention?

### **1.6 Significance of the Study**

The aim of Occupational Therapy is to prevent disability and enhance functional ability in Activities of Daily Living, thereby improving quality of life both for the cerebral palsy child and the family. This is a chronic condition which requires constant and regular occupational therapy intervention. However, sometimes patients are unable to attend these treatment sessions and this study therefore was to help identify the factors that hinder regular attendance and adherence to occupational therapy with the aim of finding solutions. The study will also assist in planning and implementing awareness programs on cerebral palsy and its treatment in Usain Gishu County and Kenya at large. It will further assist parents/ caregivers on building knowledge on cerebral palsy and importance of interventions. Finally it will add to knowledge and provide literature to the organization, the University and other scholars on cerebral palsy.

### **1.7 Basic Assumptions**

Basic assumptions were that there would be cerebral palsy patients brought for occupational therapy intervention at Moi Teaching and Referral Hospital and that the respondents would give true information as requested. It was further assumed that the response size would reflect experiences of the wider population in Uasin Gishu County.

### **1.8 Limitations**

Finances to carry out the study in terms of transport and purchase of research materials was a limitation. There was limited time to carry out the research. The respondents interviewed may not have been adequate to form a representative sample to reflect the true situation.

### **1.9 Delimitation**

The study was carried out in occupational therapy Department at Moi Teaching and Referral Hospital Uasin Gishu County, this being one of the rehabilitation centers and the largest hospital in Western Kenya, with elaborate and well equipped department, offering Occupational Therapeutic services to Cerebral Palsy patients. The study focused mainly on the factors influencing cerebral palsy parents/caregiver,' adherence to prescribed occupational therapy intervention. The information gathered from the study was generalized to reflect other caregivers in



Kenya. The study was undertaken using qualitative, research design with the target population being parents/caregivers of children with cerebral palsy bringing their children for Occupational Therapy at Moi Teaching and Referral Hospital.

### **1.10 Definition of Terms**

**Adherence-** the extent to which a person's behavior corresponds with agreed recommendations from a healthcare provider complying with prescribed treatment.

**Compliance-** compliance as used in this study means the ability of the parent to bring the child consistently every week for treatment. The researcher opted to use compliance and adherence interchangeably in the document to define following of treatment instructions and keeping appointments (Gail, Carmel, Lubertzky, Vered and Heiman, 201)

**Cerebral palsy-** it is a general term for a group of permanent non-progressive movement disorders that cause physical disabilities

**Communication-** The relationship between the doctor and the patient during treatment which can either be negative or positive which can affect adherence to treatment.

**Occupational Therapy** – occupational therapy is the use of treatment to develop, recover, or maintain the daily living and work skills of people with physical, mental or developmental c conditions.

**Knowledge of Cerebral Palsy-** health awareness on the condition of their disease and the ability to appreciate the importance of treatment in the management of that disease.

**Parents and Care givers-** in this study, the term “parents” refers to the child’s biological parents whereas “caregiver” refers to other carers such as grandparents, and other relatives or supporters. These two terms are used because the biological parents may not necessarily be the prime caregivers of the child or the person who brings the child for treatment to Occupational Therapy clinic.

**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 (WHO, 2000)

**Social/Economic Support-** Social and economic Support is the availability of resources for the day-to-day survival and interactions that take place that create a bond between people. This includes include the availability of finances for treatment and and social support including physical support which can contribute to adherence.

**Travelling Distance-** this is the distance needed to travel to the health facility in terms of Kilometers, and the geographical accessibility

**Waiting Time-** Waiting time is the average time the client takes between arrival and the actual beginning of service. This includes time before receiving attention from therapist, the lost income during time spent at the clinic and the time used in traveling to and from the clinic.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter covers key themes derived from review of literature that highlights the context relevance for the studies of previous related field, acknowledges the contribution made by scholars' publication, identifies the gaps and provides the way forward. A critical review is done to identify gaps thereafter and a summary is made to show how unique the study is. The review has been categorized under various sub headings.

#### **2.2 Concept of Occupational Therapy**

Occupational Therapy is an applied science and health profession that provides skilled treatment to help individuals achieve and maintain independence in all areas of their lives. Occupational therapy helps the patients acquire skills in the performance for the jobs after a disease or injuries that are necessary for independent and satisfying lives. Occupational Therapy treats any physical or mental problem that interferes with a person's ability to perform activities of daily living. Therapy can be provided for anyone from young children to older adults. Some typical injuries or illnesses are: paralysis, injury to a hand, joint disease,

injury that limits movement, cognitive impairments, inability to perform personal care tasks, activity of daily living (ADL), and many more.

Occupational Therapy uses activities, exercises and leisure activities to treat and develop, recover, or maintain the Activities of Daily Living(ADL) and work, skills of people with physical, mental or developmental condition. Its main aim is to restore function, compensate, and prevent slow deterioration of functioning in every area of a person's life with client-centered approach being the main approach which places importance on the progress towards the client's goals. The main aim of occupational therapy intervention is the adaptation of the environment, modifying the tasks, teaching the client/family in order to increase participation in and performance of Activities of Daily Activities, particularly those that are meaningful to the client.

The ultimate aim of occupational therapy is therefore to enable the patient be as independent as possible and be able to participate in performance of Activities of Daily Living of daily which are meaningful to them. Occupational Therapists use a family-centered philosophy by working closely with families in order to address their concerns and priorities for their child. They address issues relating to sensory, cognitive, and motor impairments, which is as a result of Cerebral Palsy, affecting the child's ability to perform self-care activities, productivity, or leisure.

Parent counselling is an important aspect of occupational therapy treatment with regard to optimizing the parent's skills in caring for and playing with their child to support improvement of their child's abilities to do things. According to (Specht J. 2000) stigma can be a barrier to treatment. Occupational Therapists can address these barriers through teaching and enlightening the parents and community about Cerebral Palsy, thus reducing stigma and enhancing participation, Shack N and Eastwood D.M (2006).

Finally, occupational therapists take children's preferences into consideration in terms of cosmetic appearance when prescribing or fabricating adaptive equipment and splints. This is important as appearance may affect the child's compliance with assistive devices, as well as their self-confidence, which may affect adherence to occupational therapy participation.

### **2.3 Adherence**

Adherence has been defined as: “the extent to which a person's behavior corresponds with agreed recommendations from a healthcare provider” ([WHO, 2003](#)). It also refers to the patients desire to participate fully with the medication and their positive attitude towards the treatment as well as collaboration with their health care provider within occupational therapy. Adherence is viewed in many dimensions ([Kolt et al., 2007](#)), which include attendance at appointments to therapy,

following advice on treatment, undertaking prescribed home programs, following the frequency of prescribed appointments as advised and parent/caregivers' participation on treatment.

Many factors related to the patient, the healthcare provider and the healthcare organization are thought to influence patient adherence with treatment ([Miller et al., 1997](#)). Adherence to treatment and medication is crucial to the success of treatment and its outcome. According to [Miller et al., \(1997\)](#) factors related to the patient like their psychological issues, temperament, and their level of knowledge of the disease and their beliefs; the healthcare provider factors like their attitudes towards clients, their personal problems affecting their performance; and the healthcare organization, like the availability of facilities and the organization of services, are thought to influence patient adherence with treatment. Within Occupational Therapy it is not clear which factors act as barriers to adherence.

### **2.3.1 Poor Adherence**

Poor adherence to treatment has been identified as a problem across a number of healthcare disciplines (Vasey, 1990; Friedrich et al., 1998; Campbell et al., 2001). The concept of adherence can be viewed from different dimension. This could relate to appointments attendance, following advice or undertaking prescribed exercises. Studies suggest that non-adherence with treatment regimen and exercise

performance could be as high as 70% (Sluijs et al., 1993) and may be particularly poor for unsupervised home exercise programs. The impact of non-adherence on treatment outcome, and strategies which aim to enhance treatment adherence are required for clinical practice.

### **2.3.2 Consequence of Non-Adherence**

From the perspective of healthcare providers, therapeutic compliance is a major clinical issue for two reasons. Firstly, non-compliance could have a major effect on treatment outcomes and direct clinical consequences. Non-compliance is directly associated with poor treatment outcomes. For therapeutic non-compliance in infectious diseases, the consequences can include not only the direct impact such as treatment failures, but also indirect impact or negative externalities as well as the development of resistant microorganisms ([Sanson-Fisher et al 1992](#)).

It has been shown that almost all patients who had poor compliance with drugs eventually dropped out of treatments completely, and therefore did not benefit at all from the treatment effects ([Lim and Ngah, 1991](#)). Besides undesirable impact on clinical outcomes, non-compliance would also cause an increased financial burden for society. For example, therapeutic non-compliance has been associated with excess urgent care visits, hospitalizations and higher treatment costs ([Bond and Hussar 1991](#), [Svarstad et al 2001](#)). It has been estimated that 25% of



hospital admissions in Australia, and 33%–69% of medication-related hospital admissions in the USA were due to non-compliance with treatment regimens ([Sanson-Fisher et al 1992](#); [Osterberg and Blaschke 2005](#)). Additionally, besides direct financial impact, therapeutic non-compliance would have indirect cost implications due to the loss of productivity, without even mentioning the substantial negative effect on patient's quality of life.

#### **2.4 Factors Influencing Adherence to Occupational Therapy**

Various factors have been identified in the available literature as having important influences on adherence. These include social, economic and behavioral factors, which play an important role on healthcare benefit to the patients and can influence adherence to prescribed therapeutic services, positively or negatively. According to Rosenbaum and Steward (2006), Factors that can affect adherence are financial constraints, lack of improvement on the condition, and the distance the patient has to travel seeking treatment.

Patient/caregivers adherence to treatment can be affected by the interactions between the family system, the patient/caregivers and the external environment. The way the patient is treated in the hospital during treatment can also affect adherence to treatment in future (Kerkorian Mekay and Bannon 2006). On the other hand good handling and encouragement is likely to motivate the patient to

follow the treatment as prescribed. It is said that positive experience of the previous interaction with clinicians is associated with positive intentions to seek treatment in future, whereas negative experience and attitude will produce the reverse effect on treatment in future. (Kazdin and Wassell 1999), assert that families who experience fewer barriers are likely to carry out treatment prescriptions than those who experience more barriers. These findings suggest that compliance to therapeutic interventions can be influenced by factors that can act as barriers to treatment attendance.

#### **2.4.1 Travelling Distance to the Clinic**

The distance needed to travel to the health facility and the geographical accessibility can be a barrier to participation and the continuation of the treatment by patients/caregivers. Ease of travel can be a barrier if the patient finds it difficult to get means of getting to the hospital. Poor access to treatment facility increases economic expenses that affect compliance with the required prescribed treatment (Beardley, Wish, Fitzelle, O'craby and Arria (2003). Geographical location of the health facilities is a determinant of the access and adherence of the treatment regimen by patient /caregiver of children with cerebral palsy.

For parent/caregivers who are employed, it is difficult to get time off to get the patient to treatment due to frequency of treatment. Studies indicate that distance

travelled for treatment and the length of stay in treatment facility affects adherence to that treatment. In a study by Reif, Golin and Smith (2005), in North Carolina USA, on barriers to accessing HIV/AIDS treatment found that 58% of participants reported that, long distance travelled and unavailability of transportation services as the main factor to adherence to the required treatment regimen. These studies indicate that the location of the health facility can determine the access and utilization of medical services. In a study in Ghana, Tolhurst and Nyongator (2006) found that distance travelled to health facilities, long waiting times and negative attitude of health care providers were major barriers to the access of health care services. A study in Tanzania by Olova, Munoz, Lynch, Mkocho and West (1997) also found that long distance travelled and high costs of transportation to the health facility affected adherence utilization of surgical treatment by patients with trichiasis.

#### **2.4.2 Communication between Caregiver and Clinician**

The relationship between the doctor and the patient has been shown to be strongly associated with adherence (Ciechanowski, Katon, Russo, and Walker, 2001). Data obtained from various researches further suggest that medical providers view communicating with patients about adherence issues as an essential component of the health care services. Good patient/doctor relationship can contribute to improved adherence, but other factors can produce reverse effects. The

doctor/ patient relationship seems to be an important factor to adherence, which include the process of inquiring for diagnosis, examining, prescribing, and interaction. Poor clinician/patient communication during this process can result in the following effects which can affect adherence:

#### **2.4.2.1 Caregiver's Attitude towards Clinician**

Attitude of caregivers towards the health care providers can contribute to adherence. (Buck, Jacoby, Barker and Chadwick 1997). This is the first impression the client forms towards the clinician which can either create a negative or positive attitude towards the clinician, and in turn affect the way the patient responds to treatment. Positive attitude towards the client can improve adherence to treatment offered by that clinician. If the clinician is complicated in giving instructions the patient may not be able to follow the treatment well and may not be encouraged to come back for further treatment. Good health provider attitudes towards patient have shown to enhance health provider relationship that results in satisfaction with the treatment given and more communication with clients (D'Ambruoso, Abbey and Hussein, 2005).

#### **2.4.2.2 Clinician-Patient Interaction**

A poor clinician-patient interaction is reported to be a barrier to utilization and adherence to health care services in many African countries. A study conducted

on patients with epilepsy in USA, Buck et al (1997), found that patients who had a regular interaction with their physician about epilepsy had a better adherence than those who visited the physician irregularly. Regular interaction by the client and the physician can boost the relationship between client and the health care provider. For example in a study done by Sharkawy, Newton and Hartley (2006) in Kenya found that parents of children with epilepsy who had unpleasant experiences with clinicians in health care facilities stopped taking their child for treatment. Studies have found that compliance is good when doctors are emotionally supportive, giving reassurance or respect, and treating patients as an equal partner ([Moore et al 2004](#); [Lawson et al 2005](#)).

Adherence to treatment seems to be related to the quality, duration and frequency of interaction between the patient and doctor. The doctor's attitude towards the patient and his ability to elicit and respect the patient's concerns of the client, and to provide appropriate information and demonstration of empathy is of the utmost importance (DiMatteo MR. (1994). Social and economic factors include: time commitment, cost of therapy, income and social support.

### **2.4.3 Social/ Economic Support**

Social and economic factors often combine to yield poor adherence. Social and economic factors include the availability of resources for the day-to-day

survival and interactions that take place and create a bond between people. Poverty among people is likely to affect adherence, as financial resources may need to be directed elsewhere. Apter, Reisine, Aflex, Brown Schectman (1994) suggests that individuals of low socio-economic status have an increased risk of medication nonadherence.

#### **2.4.3.1 Economic Support**

There is some evidence that the economic cost associated with medication influences adherence. (Apter, Reisine, Afleck, Burrows, and Zuwallck, 1998; Brownbidge and Fielding, 1994; Schectman, Boubjerg, and Voss, 2002; Shobhana, Begum, Snehalatha, Vijay, and Ramachandrn, 1999), suggest that individuals of low socio-economic status have an increased risk for medication nonadherence. Patients not being able to afford their medication may contribute to patients' nonadherence, (Snodgrass, Vedanarayanan, Parker, and Parks (2001) found decreased adherence in populations where patients have applied for supplemental security income.

#### **2.4.3.2 Social Support**

Social support refers to the information, clarification, assurance and reassurance that individuals receive from others (Friedman, 2002. P.13) Social support for adherence is defined as encouragement from family and friends for the

patient to co-operate with the recommendations and prescriptions of a health professional (DiMteo, 2006). It refers to information, clarification, assistance and reassurance that an individual receives from others. Social support can be in the form of financial support, caring or physical support. The expression of concern and encouragement from others to engage in health-promoting behavior, including medication improve adherence to treatment.

Considerable research has demonstrated consistently that social support is a strong predictor of medical adherence (e.g. Bearmen and La Greca, 2002; Simoni et al., 2002). Similarly, a review by Hogan, Linden and Najarian (2002) found that effective social support have been associated with enhancing positive health outcomes. These tangible support such as goods e.g. money, food or offering an alternative perspective; and emotional support that may include reassurance that the patient is cared for and valued by others (House, 1981). Social support can be viewed in two dimensions. These are Physical support and financial support.

#### **2.4.3.3 Physical Support**

Patients like to be as close as possible to people they know when they are sick. The patient feels well cared for when they are served by loved one like parents, spouses and children. There is considerable evidence that positive support is associated with positive health outcomes. According to e.g. (Bearman & La

Greca, 2002; Simoniet al., 2002), social support is a strong predictor of medical adherence. Low levels of family support contribute to non-adherence to treatment. Some patients believe they would more readily participate in treatment if accompanied by someone close during their treatment ([Milroy and O'Neil, 2000](#); [Campbell et al., 2001](#)). The support provided by the clinician, the development of the patient–practitioner relationship and positive feedback from the health care provider can also increase adherence ([Sluijs et al., 1993](#); [Campbell et al., 2001](#)).

It is reported that patients who had emotional support and help from family members, friends or healthcare providers were more likely to be compliant to the treatment. The social support helps patients in reducing negative attitudes to treatment, having motivation and remembering to implement the treatment as well.

#### **2.4.3.4 Financial Support**

Cost is a crucial issue in patient's compliance especially for patients with chronic disease as the treatment period could be life-long ([Connelly 1984](#); [Shaw et al 1995](#); [Ellis et al 2004](#); [Ponnusankar et al 2004](#)). Healthcare expenditure could be a large portion of living expenses for patients suffering from chronic disease including cerebral palsy. Cost and income are two interrelated factors. A number of studies found that patients who had no insurance cover ([Swett and Noones 1989](#); [Kaplan et al 2004](#); [Choi-Kwon 2005](#)), or who had low income ([Degoulet et al 1983](#); [Cockburn et al](#)



[1987](#); [Shea et al 1992](#); [Frazier et al 1994](#); [Apter et al 1998](#); [Berghofer et al 2002](#); [Benner et al 2002](#); [Ghods and Nasrollahzadeh 2003](#); [Hernandez-Ronquillo et al 2003](#); [Mishra et al 2005](#)) were more likely to be non-compliant to treatment. However, even for patients with health insurance, health expenses could still be a problem. More than one in ten seniors in the USA reported using less of their required medications because of cost. Nevertheless, in other cases, income was not related to compliance level ([Norman et al 1985](#); [Lim and Ngah 1991](#); [Patal` and Taylor 2002](#); [Stilley et al 2004](#); [Wai et al 2005](#)). In Singapore, a study on chronic hepatitis B surveillance found that monthly income was not related to patient's compliance with regular surveillance ([Wai et al 2005](#)).

Studies in developing countries indicate that parents who are referred to a facility far away from their residence may not be able to adhere to that treatment due to cost of travel. According to Beardsley, Wish, Fitzelle, O'Grach and Arria (2003), the distance travelled to and from treatment imposes costs on parents/caregivers in form of time, commitment and increased expenses that affect adherence with required prescribed treatment.

#### **2.5.4 Waiting Time**

Waiting time is the average time the client takes between arrival and the actual beginning of service. Waiting time can be viewed from different dimensions.

This include: time before receiving attention from clinician; lost income during time spent at the clinic; the travel time to and from the clinic and the time spent in the hospital on consultation with the doctor. Waiting time can also be in terms of waiting to be given services by the clinician. If the clinician takes a long time to offer this service, and if the patient perceives the health provider as ignoring him, they might not adhere that treatment.

Waiting time can also be in terms of lost time in travelling to seek treatment. Patients and caregivers like to wait for treatment as short a time as possible in the health facility. According to Lonroth, Tram, Thuong, Hoang, and Diwan (2001), treatment regiments, regular visits and long waiting time at each visit are inconvenient for the patient and caregivers and they are less likely to keep the appointment as required. According to Waseem, Ravi, Radeos and Gauti (2003), excessive waiting for treatment on queues may become stressful and intolerant to the caregiver, which can result in dissatisfaction with the healthcare. Inability to get time off from work to attend treatment can threaten compliance. Long distances can constitute waiting time due to the time taken to reach the treatment facility. A shorter traveling time between residence and healthcare facilities can improve patient's adherence ([Gonzalez et al 2005](#)). Also a short time on the line can encourage the patient to keep appointments in future. Waiting time can be in terms of the duration the patient takes to complete the treatment or to be healed, while

travelling time is the time it takes the client to arrive at the clinic and back home. These factors can influence adherence to treatment regimen.

#### **2.5.4.1 Duration of Treatment**

Acute illnesses are associated with higher compliance than chronic illnesses ([Gascon et al 2004](#)). In addition, longer duration of the disease may adversely affect compliance ([Farmer et al 1994](#); [Frazier et al 1994](#)). Similarly, a longer duration of treatment period might also compromise patient's compliance ([Menzies et al 1993](#); [Ghods and Nasrollahzadeh 2003](#); [Dhanireddy et al 2005](#)). However, some studies about chronic diseases found that longer duration of the disease resulted in good compliance ([Sharkness and Snow 1992](#); [Garay-Sevilla et al 1995](#)), and newly diagnosed patients had poor compliance ([Caro et al 1999](#)). This may indicate that compliance is improved because patient's attitude of denying the disease is reduced and they accepted treatment after years of suffering from the disease.

#### **2.5.4.2 Travelling Time**

A shorter traveling time between residence and healthcare facilities could enhance patient's compliance ([Gonzalez et al 2005](#)). Patients may not be able to take time off work for treatment as a result, their rate of compliance could be threatened. In an observational study in Malasia on housewives with tuberculosis ([Chuah, 1991](#)),

reported more compliance to therapy as a result of well adaptation to clinic appointment times and treatment.

#### **2.4.5 Parent/Caregiver's Knowledge of Disease**

One of the major obstacles to patient adherence to treatment is ignorance about important issues, regarding the nature of the disease and the nature of the treatments and how effective these can be. Corlett (1996) suggests that Patient's knowledge about the disease is one of the primary reasons for medication non-adherence, while medication administration and failure to appreciate the importance of drug treatment in the management of disease is also another reason. Increased knowledge and health awareness among patients/caregivers on the condition of their disease enables them to make informed decisions concerning their health needs. Patients/caregivers non-adherence to treatment appointments can be due to poor understanding of the required treatment or how the treatments work (Buttman and Svarst, 2002). When health care consumers understand interventions and how these interventions lead to improved health they are likely to adhere to the treatment protocol Levers, Brown, Drotar, Caplan, Pischevar et al (1999).

In a study on HIV related knowledge and adherence to antiretroviral therapy in New York, USA, Weiss et al (2003) also found that all the patients who participated in their study had good knowledge about HIV and adhered well with

the treatment regimen. It can therefore generally be concluded that knowledge about cerebral palsy and nature of its treatment intervention by parents and caregivers may enhance adherence with rehabilitation. Their own Knowledge, the disease affecting them and ideas about the condition and those of other family members and society at large has been shown to be directly related to compliance to treatment. Some patients lack understanding of the role their therapies play in the treatment ([Ponnusankar et al 2004](#)); others lack knowledge about the disease and consequences of poor compliance ([Alm-Roijer et al 2004](#); [Gascon et al 2004](#)); or lack understanding of the value of clinic visits.

## **2.5 Theoretical Framework**

### **Health Belief Model**

This study is guided by Health Belief Model which was created by Hochbaun, Leventhal, Kegeles, and Rosenstoch (1966).The Health Belief Model is a [psychological health behavior](#) model developed to explain and predict health-related behaviors, particularly in regard to the utilization of health service. The health belief model suggests that people's beliefs about health problems, perceived benefits of that action, barriers to the action and [self-efficacy](#), explain engagement in health-promoting behavior. A stimulus, or cue to action, must also be present in order to trigger the health-promoting behavior.

The Health Belief Model is based on the understanding that a person will take a health-related action if he perceives a given health problem as serious, and therefore more likely to engage in behaviors to prevent the health problem from occurring or reduce its severity. According to this model the parent/caregiver of a child with cerebral palsy will take action of taking the child for treatment if he/she perceives the condition to be serious. Maiman and Becker( 1974) suggests that individuals behave or adherence to treatment is based on their readiness to act in such a way that would reduce the severity of their condition. This means that the client must understand that their disease condition causes disability if one does not engage in the right treatment intervention, and therefore this helps in engaging on the right treatment regimen to reduce the severity of disabilities.

One application of the Health Belief Model, McGavock H. (1996) has been to aid in understanding of compliance with treatments. Knowledge and attitude of the client towards the disease will determine the level of compliance to treatment. Patient must believe that they actually have the disease and that they are at risk of developing complications or get the consequences of non-compliance and that their health status or their wellbeing is at risk. They must believe that by following a particular set of health recommendations the threat or severity of the condition will be abolished or reduced Griffith S. (1990). Positive correlation exists between parent's adherence and their health beliefs.

## **2.6 Conceptual Framework**

The conceptual framework explains the factors affecting cerebral palsy caregivers' adherence to occupational therapy. According to available literature there are several factors which can influence cerebral palsy parents/caregivers' adherence to occupational therapy. The Variables identified include: Distance travelled by parents taking the child for treatment; Social/Economic factors; Waiting time; Parent/Caregivers Knowledge of the disease and Communication between parent and Clinician.

According to the literature, Adherence to occupational therapy intervention can be affected by any of the mentioned factors, which could either be positively or negatively, e.g. If the distance from the treatment facility is far the client will not be willing to keep the appointments due to time and cost of travelling while on the other hand if the facility is easily accessible the client can keep the appointments. Social/economic support factors can affect adherence when the patient is not able to get social support from the family or the community. Financial support is a kind of social support which is required to enable the client access funds pay for treatment and for travelling to the health facility. Physical support is another kind of social support which requires the parent /caregiver to be given direct support like caring or helping in transportation of the child. When this is lacking there is possibility the patient will not comply with the treatment. The economic status

plays a great role in the adherence to treatment, for example poverty has been found to play a role in adherence to treatment. People with low socio-economic status have different priorities. Any money available is channeled toward meeting the basic needs of the family instead while treatment becomes secondary.

Waiting time at the health facility can influence adherence because patients do not like waiting for long periods. If clients are kept for long on the queues they are likely to skip treatment next time. Other factors can contribute to non-adherence for example the client's level of understanding of the condition if the client understands well the condition and the consequences of non-adherence they are likely to adhere to the treatment regimen. If the client understanding of the condition is low, they are likely not to adhere to treatment because of lack of understanding of the consequences of non-adherence. Knowledge of the disease and its effects is another variable which can affect adherence. If the parent/caregiver does not understand the disease of the child and its implication on the child's health he/she may not comply with the treatment.

Communication is another factor which can play a part in adherence to treatment. This is the interaction between the parent/caregiver during treatment. If there is positive interaction there is likelihood of the client adhering or coming back for treatment, This can be due to complicated instructions by the clinician, or the



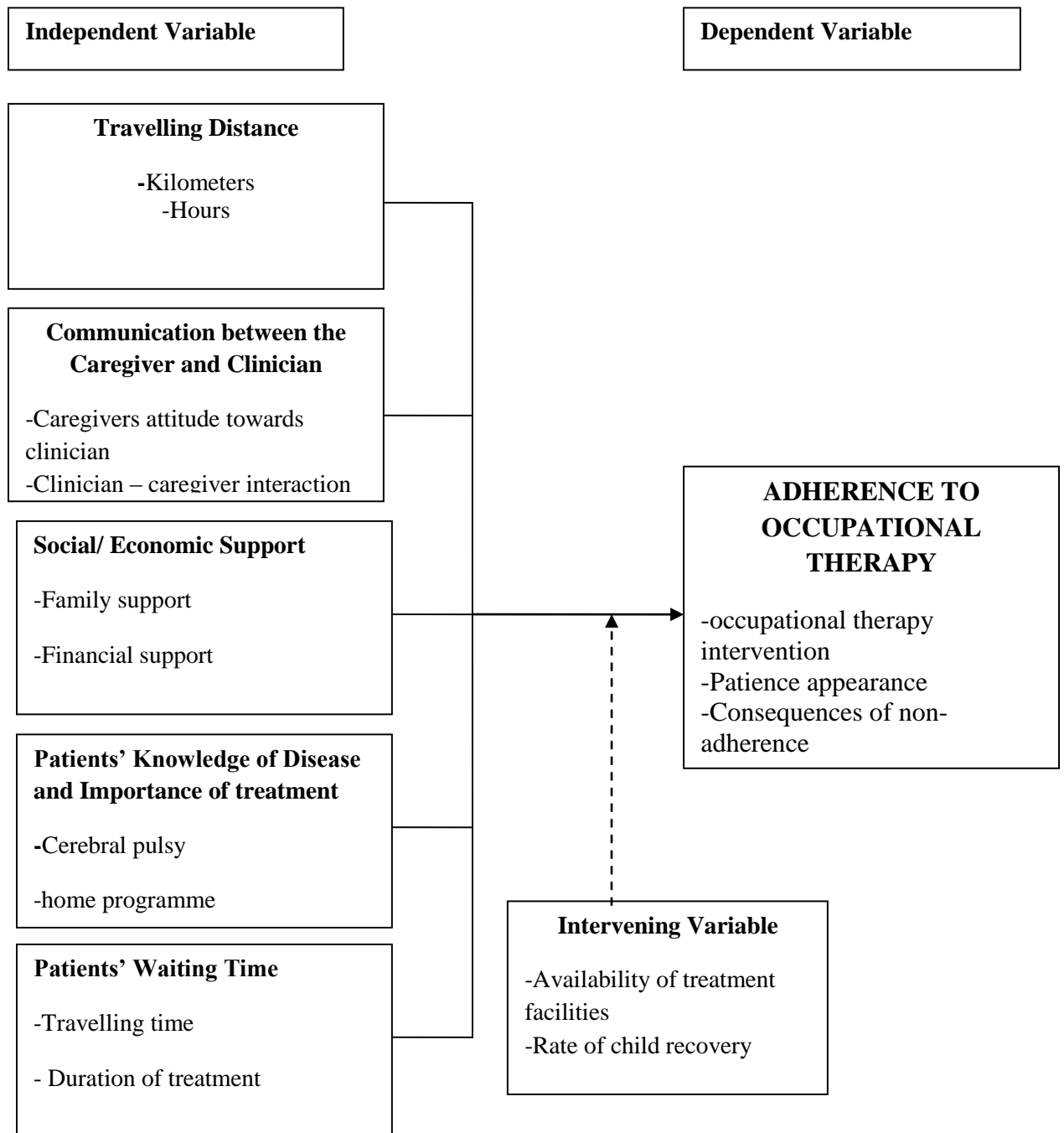
patient's inability to understand the instructions of the clinician. On the other hand if the communication is poor or the patient fails to understand the clinicians instructions the patient may not be encouraged to attend treatment. The Attitude of the clinicians towards clients can also contribute towards none adherence by the clients.

There are also other variables which can have moderating effects on adherence. These are the Intervening variable, which are not directly the factors but can have an effect on both the Dependent and the independent Variables negatively or positively. In this case the intervening variables include rate of recovery of the patient which can encourage/ discourage the parent to continue bringing the child for therapy. The other intervening variables are the availability of treatment equipment and better remunerated staff which can influence their attitude towards the clients. If the facility is well equipped the parent/caregiver will have hope on the recovery of the child and thus will be encouraged to adhere to the treatment.

The other Variables which can affect adherence indirectly are the extraneous variables which are outside factors which cannot be controlled. These include weather conditions which can affect attendance to treatment. Other variables which can have an effect on adherence to treatment are the exogenous variables. These are

variable which are dictated elsewhere which can have an effect on treatment. These include government policies which can have an effect on adherence to treatment. For example the government can bring a certain order which can affect utilization of treatment. For example the government can raise the cost of the treatment so that it is out of reach to the poor people.

**Figure 2.1: Conceptual framework**



## **2.7 Summary of Knowledge Gaps**

The literature review in this chapter has shown that parents and caregivers compliance to the treatment is crucial in determining the success and effectiveness of cerebral palsy intervention. This review explored issues related to cerebral palsy; its incidence, management, the concept of Occupational Therapy and adherence of parents/caregivers to treatment intervention. In addition this review has looked at the importance of parent compliance with cerebral palsy treatment and the consequences of poor compliance or adherence to treatment protocol.

A number of factors that act as barriers have been discussed and these include: financial constraints; Social/Economic support; communication between the clinician and parent/caregiver's knowledge about the condition; The effects of waiting time on adherence to Occupational Therapy and the effects of travelling distance while seeking for treatment in Occupational Therapy. This review has also looked at the theoretical framework underpinning this study. The theory has been identified as best in explaining the effects of adherence is Health Belief Model (HBM). The study also came up with a conceptual framework to explain the whole process of adherence to Occupational Therapy intervention.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1 Introduction**

This chapter discussed the methodology used in this study. It described the research setting, study design, the study population, sampling, the procedures for data collection and the data analysis methods, data collection tools, pilot study, the limitations, delimitations, ethical consideration and operationalization of variables.

#### **3.2 Research Design**

The study used qualitative descriptive design. Kerlinger (1969) points out that descriptive studies are not only restricted to fact findings, which may result in the formulation of important principles of knowledge and solutions to significant problems. Recorded in-depth interview was used to collect data from caregivers of children with cerebral palsy and key informants from the study site where in-depth interview guide was used to collect data. A research question and feelings is most suitable for the qualitative exploratory research and was used because of the advantages of placing emphasis on understanding the individual life experiences through examining closely, people's words and actions and it brings out the situation as experienced by the participant (Maykut and Morehouse, 1994). The qualitative approach was used to describe the problems encountered by the parents

/caregivers of children with cerebral palsy while utilizing Occupational Therapy services at Moi Teaching and Referral Hospital in Uasin Gishu County. In practical terms, it was felt that finding a large number of parents /caregivers required for the quantitative approach would be difficult since clients live far apart and also few in number.

### **3.3 Target Population**

Caregivers of children with cerebral palsy and key informants (therapists directly involved in offering therapeutic services) formed the sample population. Both Male and female parents/ caregivers were recruited from Occupational Therapy clinic at Moi Teaching and Referral Hospital to participate in the study. The study population of parents/caregivers was interviewed within a period of two weeks. This was adequate to capture a representative sample of the parents of children with cerebral palsy attending occupational therapy clinic at Moi Teaching and Referral Hospital.

### **3.4 Sampling Techniques**

Participants were recruited from caregivers of children with cerebral palsy who brought their children for occupational therapy intervention. The researcher employed purposive sampling to choose the population sample. This is a common qualitative research strategy that involves choosing subjects based on specific

characteristics and attributes in order to ensure that a range of perspectives are represented (Creswell, 1998).

Primary caregivers for a child aged 0-15 years with a diagnosis of cerebral palsy, who could speak Kiswahili or English and willing to share the experience with the researcher formed the sample. In-depth interview guide was used to administer the questionnaire to caregivers of children with cerebral palsy to collect their views, experiences and feelings on adherence to cerebral palsy clinical appointments. To get further views, two Focus Group Discussions were formed consisting of parents/caregivers of children with cerebral palsy.

According to the appointment records and the attendance registers at the occupational therapy clinic, the average number of cerebral palsy patients attending occupational therapy was 70 children per month including the new ones. Thus the following criteria was used in the selection of the sample: The child must have been attending occupational therapy clinics for not less than three months as shown in the attendance/appointment card/register; The parent/caregiver should be willing, to take part in the study. Furthermore expectations and experiences could only be best described by parents/caregivers who have experienced the service and not by observation (Oswald et al, 1998).

Based on the above criteria, only the parents/caregivers of children with cerebral palsy who were are receiving occupational therapy services at Moi

Teaching and Referral Hospital formed the sample. Selection of defaulters was identified through attendance register with the aid of key informants who are the occupational therapists directly dealing with the patient. The actively attending caregivers are those who are attending occupational therapy regularly. Caregivers of children with cerebral palsy were selected as they brought the children to Occupational Therapy. The selection was done by the researcher in collaboration with the key informants at the study site. The researcher employed the principle of saturation in determining the sample size. This means the point at which repetition of previously collected data occur, because Samples for qualitative studies are generally much smaller than those used in quantitative studies.

### **3.5 Data collection Instruments**

The study used structured interview guide to gather data. This is where the interviewer retains all control throughout the process. The researcher used the interview schedule for guidance during the interview process. This design was meant for parents and caregivers of children with cerebral palsy as well as key informants. It was to enable the researcher collect data and information that could not be directly observed or is difficult to put down in writing. Another interview guide was designed for key informants who were interviewed to shed more light and give more information concerning the study.



### **3.5.1 Piloting of the Instruments**

A pilot study is a “small study conducted prior to a large piece of research to determine which methodology, sampling, instruments and analysis are adequate and appropriate “(Bless and Higson; Smith, 2000), the study was conducted in occupational therapy department at Moi Teaching and Referral Hospital Uasin Gishu County, prior to the main research in order to test the accuracy and appropriateness of the interview guide and to restructure the procedure to be followed during the main study. Both in-depth interview guides to caregivers and key informants were piloted and modified accordingly to make questions clearer and more focused

### **3.5.2 Validity of the Instruments**

This means that the research instruments produces information which is relevant to the topic and measures what is claimed it is supposed to be measured (Kombo, 2006). Validity is the extent to which differences found with a measuring instrument reflect true differences among those being tested (Kathari, 1990). This suggests an instrument should exactly or attribute each time it is used. The study instrument was developed specifically for this study and had not been previously validated. In devising the questionnaire, the researcher attempted to assess its content validity ambiguities that could be removed or questions that did not contribute to the study purpose.

### **3.5. 3 Reliability of the Instruments**

Reliability is a measure of how consistent the results from a test are. Reliability is qualified if, when administered to test a subject twice would get the same score on the second administration as on the first (Kombo and Tromp 2006). During the development of the questionnaire, the researcher tested the instrument with 4 respondents at Moi Teaching and Referral Hospital before the start of the actual study. Their responses were compared and they were requested to give their recommendations. Their recommendations were used in some questions and the questionnaire was administered later to the same parents.

### **3.6 Data collection Procedure**

Data was collected from parents/caregivers of children with cerebral palsy and key informants in quiet settings. The researcher with the help of key informants identified the potential eligible clients who had come for Occupational Therapy intervention at the clinic. Each identified caregiver referred to the researcher to be informed about the study and were asked to sign consent form upon understanding of the specifics of the study.

A direct face-to-face interview was administered to collect qualitative data. The interview schedule was used to explore views, perceptions and feelings of the parent/caregivers and key informants on factors influencing adherence to occupational therapy intervention at Moi Teaching and Referral Hospital. Broad-

ended questions were used and the researcher made follow-up interviews to share and validate developing interpretations of caregiver's experiences and to probe specific areas that were highlighted as significant during the first interview. Interviews were audio-taped and pseudonyms were used as the identity of participants to protect family members and institution.

A list of questions were generated from literature review while one set of questions were used to study socio-demographic information such as age and sex of parent, age of child, level of parent/Caregiver's education level and parent's employment status. Another set of questions were about factors influencing adherence to Occupational therapy intervention by cerebral palsy parents/caregivers. Another set of questions was to investigate the views of the key informants on cerebral palsy adherence to occupational therapy. To verify the verbal responses they were crosschecked with the documented dates of attendance at treatment appointments registers at the clinic and the treatment cards that are given to the parents/caregivers at the clinic.

Upon completion of the interviews data was collected through focus group discussions of caregivers to triangulate the information obtained from face-to-face interviews. The researcher managed to conduct two Focus Group Discussions with the parents who met the inclusion criteria. The sessions were scheduled in one of the occupational therapy outpatient rooms.

### **3.7 Data analysis**

Data analysis involves the meaning of people's words, actions feelings expressed during the research findings from the data (Maykut and Morehouse, 1999). The researcher continued to process the data transcriptions and categorization through thorough repeated reading of the transcripts and listening to the recordings over and above again, and the emerging ideas were coded and grouped together into categories. The codes, which were abbreviations applied to a segment of words, sentences, or paragraphs were derived from the research questions, theories, concepts and important themes discussed in the literature review. Categories that were unique were left to stand alone while the related categories were further coded into themes and summary of the combined responses from the interview. The descriptive analysis of data was presented in frequency tables.

### **3.8 Ethical Considerations**

Permission to carry out research was requested from the ministry of Higher Education Science and Technology. Before the start of the research, informed written consent was obtained from parents who participated in the study which was voluntary. The purpose of the study was explained and the parents assured of their confidentiality and anonymity of the responses, to eliminate their fear that their children's treatment would be compromised. Names of parents were not recorded

on the questionnaires. The parents were assured that information obtained was for research purposes only and would not be shared with other members of staff at the clinic. They were promised that the results would be available to them at the end of the study.

The interview took place in a private room to ensure privacy of the client and caregivers of children with cerebral palsy and were given a code on the data sheet to ensure all information given by the respondent was treated as confidential information.

### **3.9 Operationalization of Variables**

To achieve the objectives of the study the researcher investigated the factors influencing cerebral palsy parents/caregivers adherence to Occupational Therapy intervention. The objectives of the study included: To assess the effect of travelling distance on adherence to Occupational Therapy; To effect of social/economic impact on adherence to treatment;; to identify the effects of parent/caregivers knowledge of cerebral palsy and its treatment on adherence; to assess the influence of communication between clinician and clients on adherence to treatment; and to assess the impact of waiting time on adherence to treatment and.

#### **TABLE: 3.1 Operationalization of Variables**

Objective	Variables	Indicators	Measurement scale	Tools of analysis	Types of tools
To assess the effect of travelling distance on adherence to Occupational Therapy	<b>Independent</b> Adherence to Occupational Therapy intervention  <b>Dependent</b> Travelling distance	Kilometers travelled and amount of money paid in fare	Ordinal scale	Descriptive statistics. tables	Frequency distribution table, and percentages
To assess the influence of communication between clinician and clients on adherence to treatment	<b>Independent</b> Adherence to Occupational Therapy intervention  <b>Dependent</b> Communication between clinician/parents	Observed attitudes towards clinician	Ordinal scale	Descriptive statistics Tables	-Frequency distribution tables -percentages
To identify the influence of socio-economic factors on adherence to Occupational Therapy	<b>Independence</b> Adherence to prescribed treatment  <b>Dependent</b> Socio-economic factors	Amount of income earned	Ordinal scale	Descriptive statistics.	Frequency distribution tables and percentages
To assess the impact of waiting time on adherence to treatment	<b>Independent</b> adherence to Occupational Therapy intervention	Number of hours waited	Ordinal Scale	Descriptive statistics Tables and pictures	Charts and percentages

## **CHAPTER FOUR**

### **DATA ANALYSIS, PRESENTATION, INTERPRETATION AND DISCUSSION**

#### **4.1 Introduction**

This chapter presents the findings in the following thematic subsections which are, broken into, Demographic characteristics of the respondents, Adherence to occupational therapy intervention, Measure of adherence and Factors that influence adherence to Occupational Therapy intervention. It also discusses findings on the influence of travelling distance on adherence; the effect of communication between clinician and the patient on adherence, the influence knowledge of cerebral palsy on adherence; effect of social/economic support; and the effect of waiting time on adherence to the treatment regimen and discussions on the implications of the findings.

#### **4.2 Study Sample**

The study investigated adherence of parents/caregivers of children with cerebral palsy to occupational therapy treatment regimen. The study sample of parents who brought their children for Occupational Therapy was recruited to participate in the study. The sample consisted of 14 parents/caregivers of children

with cerebral palsy and all the the Occupational Therapists working in the outpatient Occupational Therapy clinic at Moi Teaching and Referral Hospital in Uasin Gishu County.

### **4.3 Socio-Demographic Characteristics**

This section discussed the demographic characteristics of respondent's age, marital status, level of educational, and occupation of the respondents. The age was also investigated because it determines the quality of care for the patient due to the level of activity of the parents/caregivers. Educational level was used to measure the level of understanding of the condition of the child and the effect of the disease. Occupation was studied to find out the financial strength and support to the caregiver.

#### **4.3.1 Age of the Child**

This study collected data on the age of the child who took part in the study in order to know when the child was brought for treatment. The findings are shown in Table 4.1.



**Table 4.1 Age Distribution of the child**

<b>Age</b>	<b>Frequency</b>	<b>Percentages</b>
0-6	4	28.6%
6-24	5	35.7%
2yrs-5yrs	2	14.6%
5yrs-10yrs	2	14.6%
Over 10 yrs.	1	7.1%
<b>Total</b>	<b>14</b>	<b>100%</b>

From the study it was found that the ages of the children varied from between 6 months to 10 years. 1 child was aged above 10 years which represented 7.1 % of the total children, 3 where aged between 5 and 10 years which represented 21.4%. Children aged between 2 and 5 years were 3 which represented 21.4 % where under 2 years. 4 Children attending Occupational Therapy were under 2 years represented 28.6%. of the children in the study. An average child with cerebral palsy is not diagnosed until approximately 12 months of age when developmental milestones are noticed to be delayed, Kuban KC (1994). This could explain the findings where most of the children brought for Occupational Therapy are above 2 years. From the findings it is obvious that as the child grows the rate of attendance to treatment

decreases. This situation could be as a result of a number of factors, which could include: the child by age five years and above could have improved greatly so that the child no longer require therapy; or it could also mean that the child has grown and it is difficult to transport the child to the hospital; It could also mean that the parents became tired of attending Occupational Therapy and so they tried other treatment interventions like the herbal medicine, or some of them could have passed on or parents have migrated to other locations.

#### **4.3.2 Marital Status**

The respondents were asked to indicate their marital status and the findings are shown in Table 4.2. It was important to understand marital status because married parents were in a better social and financial position to support, which is a requisite to adherence to treatment.

**Table 4.2 Marital Status of Parents**

<b>Level of Education</b>	<b>Frequency</b>	<b>Distribution Percentage</b>
Married	9	64.3%
Separated	2	14.3%
Not Married	3	21.4%
<b>Total</b>	<b>14</b>	<b>100%</b>

The data presented showed that most of the parents were married (64.3%); the number of parents who were not married represented 7.1% while those who were separated represented 14.3% and 21.4% were not married. It was important to investigate marital status of the respondents to determine the level of support which can determine level of support caregivers receive because married people have better support than single parents. Marital status influence patients' compliance with medication positively ([Swett and Noones 1989](#); [Frazier et al 1994](#); [De Geest et al 1995](#); [Turner et al 1995](#); [Cooper et al 2005](#)).

Married parents were more likely to attend regularly for treatment than single parents. This could be because married parents have support from the other parent in the day-to-day care of the child during treatment. This could result in mothers not straining alone with the burden of care, because fathers could meet both financial support and care for the other children while the mother takes the child to the clinic. The help and support from a spouse could be the reason why married patients were more compliant to medication than single patients.

#### **4.3.3 Duration of Treatment**

Data was collected on the length of time the child had been brought to for occupational therapy intervention and the findings are presented in table 4.3

**Table 4.3 Duration of occupational therapy attendance**

<b>Duration of attendance</b>	<b>Frequency</b>	<b>Percentage</b>
Over 5 years	2	14.3%
Between 2 and 5Yrs	5	35.7%
Less than 2 yrs.	7	50%
<b>Total</b>	<b>14</b>	<b>100%</b>

From the findings most of the children with cerebral palsy who were brought for occupational therapy had been treated for less than two years. This represented 50% of the total patients with cerebral palsy. Children who had been attending occupational therapy between 2 years and 5 years in treatment represented 35.7 %. While those with duration of 5 years and over represented 14.3 %. The findings could be interpreted to mean that the high number of patients who are less than 2 years brought to the clinic was due to their weight because they still young and therefore light to carry. This agrees with the findings by Power, (1985), who found that patients who receive family support and encouragement improve faster and have better results. This can be assumed that children who are persisting in treatment get enough support from their families and therefore improve faster.. In this study, parents reported a number of difficulties they met in complying with treatment regimen.

#### 4.4 Adherence to Treatment

In this study adherence was described as the parent's ability to bring the child for occupational therapy intervention as prescribed by the clinician. Adherence to treatment was measured by parental report on keeping treatment appointments and crosschecking with dates of treatment sessions attended, as documented in the attendance register at the clinic. Results from the study indicated that 90% of the parents who participated in the study were compliant. 80% of those who were compliant were from the urban areas while 20% were from the rural areas. From those caregivers who were interviewed 1 respondent had not managed to attend the clinic in the last 1 month, while 6 respondents had managed to bring their children for occupational therapy without missing their sessions in the same month. The respondents were asked to indicate what motivated them to attend treatment, and they all reported that, "I am hoping that the child will get well soon." some of the reasons that encouraged them was the kindness of the therapists and commitment to make the children well.

It could be argued that the good compliance was because most participants were women. Women are expected to take the role of care taking and appear to do so by trying to fulfill treatment requirements, so that their children can improve (Owen, Hoagwood, Horwitz, Leaf, Podszus et al (2002)). The results of this study are consistent with other studies on compliance with parents. In a study in Saudi Arabia on compliance with treatment appointments and medication in paediatric

rehabilitation by Al-Faris, Abdughani, 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 medication and keeping treatment appointments. A similar study, study in Israel on compliance with prescribed rehabilitation therapy in Jewish and Bedouin population by Gali et al (2001), found that 89% of the Jewish parents and 78% of the 83 Bedouin parents that participated reported they were compliant with exercise treatment regimen.

One other factor that could have contributed to the good compliance is improvement of the condition of the child during treatment. 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 vital factor for motivating patients and caregiver to adhere to the recommended treatment requirements.

#### **4.5 Factors influencing Adherence to Treatment**

When planning for rehabilitation services especially for children with physical impairments in many developing countries, it is usually assumed that all the children who are affected and their caregivers will attend these rehabilitation services. However, in reality, not all children requiring evaluation and treatment do attend.(Whitworth, Pickering, Mulwanyi, Ruberantwari, Dolin and Johnson, 1999). In addition, even those parents who do attend experience a number of barriers,

which are not well understood by the rehabilitation care providers and if not addressed could affect effective utilization of rehabilitation services by the community.

The following factors were tested and the respondents had various responses on the influence of these factors on adherence to Occupational Therapy intervention. The barriers that were assessed included; Travelling Distance; communication between clinical and the parent/caregiver; Social/economic support; Knowledge of cerebral palsy and importance of treatment, and waiting time at the clinic.

#### **4.5.1 Travelling Distance**

Parents covered variable distances from their homes to the hospital in pursuit of treatment for their children at the occupational therapy clinic. From the findings 42.9% left within town and only spent an average of 1 hour to reach the hospital, while the furthest left 50 km away from the clinic and reported that they took 7 hours to and from the hospital for each visit. All the respondents agreed that distance to the hospital played a role in the adherence to treatment.”... *I live in another county and I have to connect two vehicles to reach the hospital ...*” reported respondent 7.

“... *on the clinic day I take the whole day to attend the clinic...*” was a reply from respondent 2. All the respondents agreed that on a clinic day one is not able to do

any other duties due to the time it takes in travelling and going through the treatment”... *I am not able to go to carry out my business on the clinic day...*” reported Respondent 5 who is a vegetable vendor. Respondent 6 and 8 had to content with caregivers taking their childrent to the hospital because their employers do not understand their child’s condition. *“I have to give various excuses to accompany the child to hospital...”*. When asked if there is any other hospital near them that can offer occupational therapy services, they all replied that there was none.

**Table 4.4 Distances in Km.**

<b>Distance Travelled in Km.</b>	<b>Frequency</b>	<b>Percentage(%)</b>
Less that 5 Km.	5	35.7%
5-10 Km	3	21.4%
10- 20Km	1	7.1%
20-50Km	3	21.4%
Over 50 Km	2	14.4%
<b>Totall</b>	<b>14</b>	<b>100%</b>



All parents who travelled 10 Km or less to the hospital were considered to be living near the hospital and therefore spend less on transportation to the hospital. They also had the advantage of the good transport system in the town including well tarmacked roads and availability of *matatu* vehicles. On the other hand it was difficult for the respondents who stayed far away to get to the hospital on time due to distance and the hardships encountered due to the state of the roads. The cost of travelling was also a problem for those who stayed far away and said they could not afford because most of them were not working. One respondent reported that it is very expensive to bring the child to the clinic *“I have to pay for myself and another person who accompanies me to the clinic.”* Those who came from a distance of 5 Km. from the hospital were considered to be living near the hospital whereas those who travelled 50 Km or more were considered to be living far away from the hospital.

It is reported that in developing countries the effects of distance on service use becomes stronger when combined with lack of transportation and poor roads, which contributes towards indirect costs of visits to the health care facilities. As discussed in the chapter, parents who travelled short distance were more likely to adhere to treatment regimen than those who travelled long distances. These results support the findings of Beardly, Wish, Fitzelle, O’Grady and Arria (2003) in USA, who found that the distance travelled to the treatment centre, was significantly associated with treatment adherence. This Indicates that as the economic costs of

treatment attendance increased with distance, the ability diminishes for clients to stay in treatment longer (Beardly et al 2003). It can be suggested that minimizing the geographic distance that parents must travel to the hospital through use of community outreach clinics, might reduce transportation costs and improve adherence to treatment regimen.

#### **4.5.2 Communication between Caregiver and Clinician**

The study asked about their views on their communication with the clinician during treatment, as a way of assessing the interaction between the parents and clinicians during treatment process. Most caregivers were of the opinion that they were treated well and had no problem with the clinician and therefore had no reason to skip their appointments. They reported that they were handled well during treatment. “.. *The therapists are always very ready to explain to us any questions we ask...*” Caregiver 1, 2, 4 and said “*therapists are always very kind and friendly. They are kind to my child...*” in a Focus Group Discussion they all agreed that the clinicians were friendly and always motivating them to keep their appointments. When asked if they understood the treatment instructions given to them by the clinician they all agreed that the clinician takes time to explain to them on their role in the treatment of the child. Respondent 12 reported that “ *the therapist gives us home programs and demonstrates clearly* “

It can be stated that patient-prescriber relationship is a strong factor which affects patients' compliance. The findings are in contrast with the findings by Sharkawy, Newton and Hartley (2006) in Kenya, in which he found that parents of children with epilepsy who had unpleasant experiences with clinicians in health care facilities stopped taking their child for treatment.

#### **4.5.3 Social/Economic Support**

An important determinant of treatment adherence was social support which refers to the information, clarification, assistance and reassurance that an individual receives from others (Fieldman, 2002, P, 13). Two aspects of social support were investigated. These were physical support provided to the parents at home and the financial support that is required for the parent and the child to attend treatment. Social support include encouragement and advice given to the patient in order to motivate the patient to continue with treatment. The findings showed that most of the respondents had poor social support. For example respondent 3 who had a small baby found it difficult to bring the child for treatment because there was no one to take care of their homes when they were away to attend treatment “ *..it is like I have two babys. I lack someone to take care of my small baby so that I can bring the this child to the hospital*” reported respondent 13. Most of the respondents reported that they are not able to meet the cost of treatment, “ *I had to be done a fund raising in the church for me to come to the hospital and when the money is over I don't know how I will manage to come*” was the response fro respondent 5

Strain and burden of domestic responsibilities and care could be a barrier to attending treatment 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 either kind of support not only found it hard to balance domestic responsibility with the treatment requirements but also could not afford the necessary costs, which resulted in poor adherence with the treatment regime. There is considerable evidence to suggest that positive social support is associated with positive health outcomes. Participants identified that since much of Kenya is below the poverty level, economic factors may act as a barrier to attending occupational therapy. For most patients Occupational Therapy treatment is not covered by insurance and cheaper alternatives are often not available. The participants suggested that increasing awareness to the Government to introducing home-based exercise, occupational therapy might help to tackle the issues of cost.

The study investigated whether having someone to take care of other children at home influenced the parents bringing the child for treatment. 20% of parents indicated that they had someone at home to take care of their other children while 80% indicated that they did not have. This was reported as one of the factors that enabled or hindered them from bringing the child for treatment every week. Respondent 7 said “.... *My child has really improved but I am not able to take the child to hospital always...infact the child could have done much better if I had someone to take care of things at home while I go to the hospital...*”

A few caregivers said they received support from their husbands, and other members of the family, while reported that they received support from neighbors in form of donations and fundraisings. Caregiver 2 said “*my husband gives me money for transport every time she has to take the child for treatment...*” respondent 5 said that her husband started supporting her after neighbors had noticed some improvement in the child’s condition. She said that the neighbors had helped to talk to husband to change his attitude towards the child and started offering support to enable the mother and child attends treatment regularly. Lack of support from relatives has been identified as a barrier affecting adherence to occupational therapy intervention at Moi Teaching and Referral Hospital. These results are similar to those from North East London (Lawlor K. Mihayov S. Welsh B. Jarvis S, 2001).

It has been shown that family support provided by the immediate family members directly affect the health of caregivers and their behaviours. The study found a significant association between physical and financial support and compliance with the treatment regime. These results correlates with the 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 regiment for their children.

#### **4.5.3.2 Financial Support**

The findings identified who provided the financial support that enabled parents to bring the child for treatment at the Occupational Therapy clinic. A majority of caregivers had failed or defaulted on Occupational Therapy several times due to lack of money to pay for transport. Respondent 1 said “...*I had no money to pay for transport to travel to the hospital since my husband is not working or doing any business...*” some caregivers said they come from very far away and they have to connect two vehicles to reach the hospital. Some have to use motorcycles as transport to reach the main road. Some said they can afford money for treatment but transport is very expensive when they have to attend therapy more than once in a week.

Respondents indicated that financial considerations and relatedly, transport problems, had a significant impact on adherence. In many ways the social context characterized by limited community resources such as a poor transport infrastructure played a role in determining patient’s clinic attendance.

The study found a significant association between physical support and financial support and 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, Roland 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 physical support received from family members relieved these mothers, of the burden of having to take care of the cerebral palsy child.

#### **4.5.3.3 Transport Cost**

In establishing the cost of access of healthcare services, the important starting point is the distance from home to the nearest health facility, which determines how much the patient will pay before accessing the health services (Hjoptberg and Mwikisa, 2002). In the present study 8 parents indicated that they found it expensive to bring their child for treatment every week and that the expenses incurred in bringing the child for treatment was beyond their means. This finding could be expected considering the fact that 70% of the parents who participated in the study were unemployed.

Respondent 3 who stay 10 km away said that she can afford the treatment costs but not transport costs because she has to be accompanied and so she has to pay for double fare. The study asked also parents how much they were paying to and from the hospital. The results showed that the minimum amount of money parents paid for transport was Ksh.100 for parents who come from around town and over Ksh.1000 for those living far away from the hospital.

Majority of parents who failed to attend treatment reported that they lacked money for transport. Respondents No 2 *“I had no money to pay for transport to travel to the hospital since my husband and I are not working, nor doing any business.”* Some caregivers had stopped attending treatment services because they lacked money especially those who came from far away from the hospital. Respondent 9 who is employed said and *“... if I and my husband where not working it could have been impossible to bring the child to the hospital due to the cost of transport..”* some caregives admitted that during the rainy season the roads are impassible and so they have to use a motorcycles to reach the hospital. If two people have to accompany the child then they have to pay almost Ksh.1000 per visit

**Table 4.5 Source of Finance**

<b>Source of finance</b>	<b>Frequency</b>	<b>Percentage(%)</b>
Father	5	35.7
Mother <sup>4</sup>	6	28.6
Grandparents	2	14.3
Other	2	14.3
<b>Total</b>	<b>14</b>	<b>100%</b>



An analysis on the cost of transport showed that, 82% of parents who were interviewed indicated that transport expenses incurred in bringing the child for treatment every week was very expensive. The parents were also asked how much money they paid to and from the hospital and the results showed that the minimum amount of money parents paid for transport was Ksh.200 on average.

#### **Table 4.4 Source of Finance**

While parents paid Ksh.600 for transport around town. The majority of parents who come from outside the town paid over Ksh. 1000 for one trip. Most of those caregivers 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. The findings identified who provided the payments for the child's treatment and there were various responses. These included fathers, mothers, grandparents and other well-wishers including fundraisings. Respondent 2 said “.. *I am depending on wellwishers to enable me come to the hospital.*”

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 (Hjortberg and Mwikisa, 2002). The results of this are consistent with findings of Ellis, Gogel, Roman, WatsoIndyk et al (2006). In a study on adherence to short-term drug regimes in Kenya where it was found that over 65% of the parents

reported having complied with the prescribed treatment for their children but report financial problems as one of the major barriers they encountered in attempting to access the required treatment regime.

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 cheap. This result also supports earlier findings by Kim and Tellen (2004), in Korea where it was found that the child's dental care were less likely to follow up on the treatment at the dentists. Similarly, Kilter, Salgado, Moulton, Neito, Contreras et al (2003) in a study on factors constrains adherence to referral advice for severely ill children in Ecuador found that high transport costs to health centers were significant constraints that prevented mothers from completing a referral program and their retention in treatment.

Since most of these parents who attended the clinics 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 transport costs and other necessary expenses. 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 used private transport e.g. in Kenya patients use motorcycle from home to reach main roads. This mode of transport increases the cost of transportation

affecting most parents. These costs could be minimized if the treatment services for cerebral palsy could be extended to the community.

In conclusion it could be argued therefore that mothers who had neither of support not only found it had to balance domestic responsibilities with the treatment requirements, but also could not afford the necessary cost, which resulted in poor compliance with the treatment regimen.

#### **4.5.4 Waiting Time**

Parents indicated how much time they spent in occupational therapy clinic and how much time they took before they were given service at the clinic. The least time spent was 30 minutes and the longest time was 3 hours. On average most parents spent 2 hours in the clinic. When asked what they feel about the time taken before they were served, all the respondents reported that they were served in good time at the clinic, but the time taken on the way to and from the clinic was demotivating. “ *here we follow a queue and so people are served as they arrive,*” was a response from respondent 4, when asked to comment on the time they took to be served. This is contrary to the findings of a research done by Waseem, Ravi, Radeos and Gauti (2003), who found that long waiting on queues and excessive waiting for treatment may become stressful and intolerant to the caregiver which can lead to dissatisfaction with the healthcare, and may lead to poor compliance with the treatment recommendations. The findings are shown in table 4.6

**Table 4.6 Waiting Time**

<b>Duration</b>	<b>Frequency</b>	<b>Percentage</b>
Less than 30 min	7	50%
Approximat 1 hr	4	28.6%
Over 2 hrs	3	14.3%
<b>Total</b>	<b>14</b>	<b>100%</b>

All the parents agreed that 30 minutes was appropriate for them to wait for treatment, and most parents suggested one hour to be the most convenient length of time to wait for treatment. Although most parents did not report this as a factor which could affect adherence to treatment, most parents reported it can a major barrier, to the treatment requirements.

#### **4.5.5 Parent's Knowledge of Cerebral Palsy**

Theorist have proposed that a mismatch between the caregiver and the therapists' expectations for treatment may lead to dissatisfaction with services and may lead to poor adherence to the treatment regime (McCobe,2002). For example if caregivers have little knowledge about the condition and are unfamiliar with the process of treatment, they may have unrealistic expectioations about the condition and outcome, and if they are unfamiliar with the process of treatment, they may

have unrealistic expectations about how long the treatment will last, how quickly the child's problem will resolve and to what extent they will be expected to participated in treatment( McCobe, 2002).

Despite the inadequate knowledge prior to diagnosis 74% of parents indicated they understood the consequences of not following the treatment regimen. This indicated that these parents learned about some aspects of cerebral alsy and its treatment including the benefits of adhering to the prescribed treatment including the benefits of adherence, during the time they attended treatment of their children. However it is not known if this parents learning was obtained through exposure or was obtained from fellow parents who were attending treatment.

**Table 4.7 Parent's Knowledge of Cerebral Palsy**

<b>Parent's knew about cerebral palsy</b>	<b>Yes</b>	<b>%</b>	<b>No</b>	<b>%</b>
Clinician explained what Cerebral Palsy is	10	71.6%	4	28.6%
Parents understand understands their role in treatment	8	57.4%	6	42.6%
The clinician gives parents sufficient information on treatment	4	28.6 %	10	71.6%
<b>Total</b>	<b>14</b>	<b>100%</b>	<b>14</b>	<b>100%</b>

Research has shown that parent's knowledge about the condition may change after exposure to the prescribed treatment (Corickum, Rimer and Schachar, 1999). It could be presumed that parents whose children 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 may have sought some of this information from other parents who had started treatment earlier.

The parents were asked whether they had prior knowledge about cerebral palsy and its treatment and the results showed that most parents did not know about cerebral palsy before the child's diagnosis and neither were they explained what cerebral palsy was by the clinician or why they had to bring the child for treatment every week. Respondent 10 reported "... *I was not told earlier the problem of my*

*child..” the Doctor kept on telling us that the child would be well”* was a response from respondent 1 who decided to seek further treatment in another hospital when she noticed her child was not growing well. The current study revealed that the caregivers of cerebral palsy children had many knowledge gaps regarding the illness of their children. This is quite expected given the high prevalence of illiteracy among them, in addition to the low economic level. Similar low levels of knowledge and practice have been reported among caregivers of patients with various chronic diseases (Bollinger et al 2011; Rocker et al, 2012).

The results of this study are consistent with the findings of Chardwick, Jolliffe and Goldbart (2002), in Manchester, United Kingdom, on Caregivers, Knowledge of dysphasia and its influence on adherence to dysphasia management strategies.

## **CHAPTER FIVE**

### **SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATION**

#### **5.1 Introduction**

This chapter discusses the summary, conclusion, recommendations, contribution to the body of knowledge and suggested areas for further research in the following sub- themes. Based on the data and other information obtained and analyzed to answer the research questions of the study, a number of research findings were presented in chapter four. The findings are summarized in this section.

#### **5.2 Demographic Characteristics**

The study showed that the majority of the parents/caregivers were the female gender who formed 93% against 7. % of the male gender and 64% were married. A further study showed that 21.4 % of the respondents were employed while the majority was not in gainful employment and most of respondents lived in the urban areas. The study also revealed that majority of the respondents had



secondary school education. It further showed that the majority of the children brought for treatment were 2 years and below representing 35.7%

### **5.2.1 Distance Travelled to Hospital.**

The findings of this study indicated that the respondents had a problem with the distance travelled to access occupational therapy intervention. It was found that parents/care givers used more than Ksh.200 whether they came from far or near the hospital. Most of the respondents were not sure if they would continue with therapy because they did not know how they would get the money to continue therapy. This is because most of them reported that the community had to do fundraising to enable them attend the treatment. It is demonstrated by the age of the patients and the duration of therapy, where most of the children brought for treatment were below 5 years, whereas this is a long term intervention and so more older children would have been attending treatment.

### **5.2.2 Effects of Communication between Parent/Caregiver and Clinician**

Findings of the study indicated that the respondents did not have any problems with the communication with the clinician. The respondents had positive comments for the clinician where they reported that the clinician was kind and always ready to explain to them any questions they asked. They also reported that the home program given to them to follow were well explained to them.

### **5.2.3 Waiting Time in the Clinic**

All the respondents reported that they did not have any problem with the waiting time because they were served immediately they arrived. However, they reported that they had a problem on the time taken to arrive in the hospital due transport problems causing them not perform any other duties on a clinic day. This especially threaten adherence because most of the parents/caregivers are not employed and so they have to search for money most of the time both for basic needs and for hospital treatment.

### **5.2.4 Social/Economic Factors**

Most of the respondents reported that they lacked support especially physical support for their children. The parents found it difficult to get anyone to take care of the child and also to accompany them to the hospital, leaving the parent to do everything on their own. This was reported by the key informants, as a possible cause of nonadherence to treatment especially for the parents of children who are bigger. The parents reported that children become heavy as they grow and so they become tired carrying them.

The other aspects of social support was financial support. Respondents reported that they received minimal support from spouses, and the public had to conduct fundraisings to support finances needed for the child's treatment. This was reported as a problem because once the money for treatment was over the caregiver

was forced to stay at home and abandon treatment for the child. Most of the respondents reported financial hardships in connection with the financing of transportation and treatment of the child. All parents reported that the cost of transport was very high and was likely to affect adherence to treatment due to unemployment and lack of funds.

### **5.2.5 Knowledge of Cerebral Palsy and Importance of Treatment**

It was found that knowledge of cerebral palsy and its treatment did not affect adherence to Occupational Therapy intervention for some parents. Those parents who were not clear about the meaning of the diagnosis reported that they had to consult herbal medicine for the remedy of their child's ailments which affected adherence to treatment of the child. However, all parents/ caregivers who were interviewed reported that they were willing to follow the clinician's advice and the programs for the good of their child.

### **5.3 Conclusion of the Findings**

The discussion focused on the major findings in respect of the objectives of the study. The findings showed that the majority of the parents in the study were compliant with cerebral palsy treatment regimen for a certain period of time. The study found that parents had poor knowledge of cerebral palsy before the diagnosis of their child but learned more as they attended treatment. The study demonstrated significant association between adherences to treatment the parents encountered,

which included transport and travelling distance, transport costs, and knowledge of the disease, but reported positive interaction between the client and also no problems with waiting time..

The aim of the study was to investigate factors influencing Parent/caregivers adherence to Occupational Therapy intervention. The study reviewed literature on adherence to treatment and finally, the barriers parents encountered in accessing the treatment regimen. From the results of the study, it can be seen that most parents were attending the clinics at the time of the study were compliant. However the majority of parents had poor knowledge and lacked information about cerebral palsy and its treatment, and was concerned with some aspects of treatment and financial costs. On the other hand, despite their inadequate knowledge of cerebral palsy and the treatment process, all parents 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 adherence for other parents. These included financial constraints to meet transportation costs, travelling distance and inadequate knowledge of cerebral palsy.

#### **5.4 Recommendation**

The results of the study will be useful in improving service delivery to cerebral palsy children at the occupational therapy outpatient clinic in Usain Gishu

County. In addition the results will be useful in developing effective interventions aimed at enhancing utilization of services and adherence to the treatment regimen at the clinic. The 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 on time.

Considering the results of this study, and the difficulties parents experienced in attending to all treatment appointment at the Occupational Therapy clinic at Moi Teaching and Referral Hospital Uasin Gishu County, the study makes the following recommendations. These are based on the factors or gaps identified in accessing occupational therapy interventions by caregivers of children with cerebral palsy at Moi Teaching and Referral Hospital in UasinGishu County:

**a)** There is need for medical rehabilitation sector to advocate for more funding from responsible ministries, donors and well-wishers to provide adequate financial allocation to the rehabilitation sector to enable the introduction of outreach services for cerebral palsy patients.

**b)** There is need to decentralize services from main hospitals to the health centers in the community that are accessible to most patients/caregivers. This can be implemented through outreach clinics in communities that are located far away from the referral hospitals. This strategy would shorten the 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 nearer to the people.

c) The researcher also recommends that more research involving both qualitative and quantitative approaches to be done on the same topic for other referral hospitals to assess the rate of compliance of parents and clients on the difficulties that they go through in these areas. This could capture data and views of parents in different settings which could be used to develop programs that could improve the treatment of cerebral palsy in Kenya.

d) There is need to increase the number of occupational therapists so that it is easy to conduct the outreach services in the community.

### **5.5 Contribution to body of Knowledge**

The study has the following contribution to the body of knowledge,

**Objectives** - To assess the effects of travelling distance on adherence to occupational therapy intervention

**Contribution**- The treatment intervention of cerebral palsy is mostly in the training of the Activities of Daily Living. This can be achieved if the approach of intervention is geared towards home- based care. This will help the clients from travelling far and thus saving on travelling costs.

**Objectives-** To find out the influence of communication between clinician and clients on adherence to Occupational Therapy intervention;

**Contribution-** Cerebral palsy is a condition that has a potential of causing psychological effects to the affected individuals. It suggested that the curriculum for the training clinicians should include the subject on this condition and how to handle them and their caregivers and also change their attitude towards patient and their caregivers.

**Objectives-** To examine the effect of parent's knowledge of cerebral palsy on the adherence to occupational therapy.

**Contribution-** The study noted that parents were not aware of cerebral palsy and its effects on the child. This factor could be corrected if the government can initiate a project of sensitization so that the parents can recognize the sign of cerebral palsy and take their children for early intervention.

### **5.6 Suggested Areas for further Research**

There is need for future research instrument to be administered to a larger sample in order to validate the data collected in the quantitative study. Both qualitative and quantitative data may be used to develop potential interventions designed to enhance adherence among patients in the rural areas.

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## APPENDIX I

### Parent Consent,

Dear parent,

My name is Loyce Biwott, a Master's student at the University of Nairobi. I am conducting a research as part of the requirements for Master's degree in Project Planning and Management. The Title of my study is "Factors Influencing Cerebral Palsy Parents/Caregivers' Adherence to Occupational Therapy Intervention". The results of the study will be used as a guide to plan treatment intervention for improved rehabilitation services of children with cerebral palsy. I am kindly requesting for your participation in this study, by answering the questions to the best of your knowledge that I will ask you. The participation is voluntary and the information given will be confidential. If you do not wish to participate in the study, your child's treatment will not be affected in any way.

Participants Signature..... Date.....

**APPENDIX II**

**SECTION A**

**RESEARCH QUESTIONS**

**Interview Guide for the Parent/Caregiver**

**Demographic Data**

Gender of Caregiver: .....

Marital Status: .....

Residence: Rural [ ]

Urban [ ]

Address.....

Date of Birth of the child .....

**Main Questions**

1. Who has accompanied the child today for treatment?

Mother [ ]

Father [ ]

Grandparent [ ]

Aunt [ ]

2. What is your current employment status? please tick in the right box

3. What is your highest level of education? Please tick in the right box

	<b>Occupation of Respondent</b>	
1	University	
2	Self employed	
4	Housewife	
5	Retired	
6	Student	

4. Are you the biological parent of the child?

Yes [  ]

No [  ]

5. If No for the above what is your relationship with the child?.....

.....

**Adherence**

6. Do you attend treatment regularly?

Yes [  ]

No [  ]

7. If you have been attending Occupational Therapy with the child when did you start attending with the child?

Date.....

8. How often do you attend Occupational Therapy services with the child?

	<b>Frequency of attendance</b>	
1	Daily	
2	Once in a week	
3	Twice in a week	
4	Twice in a month	
5	Once in a month	

9. Have you been able to keep your appointments of occupational therapy?

Yes [ ]

No [ ]

10. If No what could be the reasons that make you not to attend the clinic regularly?.....  
.....

11. How many times have you been able to attend to this clinic in the last one month?.....  
.....

12. What are some of the factors that can motivate you to bring your child for Occupational Therapy?.....  
.....

13. Among the motivating factors which one ranks highly to you?.....  
.....

**Distance Travelled**

14. How far in kilometres, is your home from the hospital?

- Within town [    ]
- 10Km away [    ]
- 20 km away [    ]
- Over 50 km [    ]

15. How many hours do you take to reach the hospital?.....  
.....  
.....

16. Are you able to attend the hospital appointments for your child and perform your other duties on the same day?

- Yes [    ]
- No [    ]

17. If No for the above, what arrangements are there for you to get your normal work

done?.....  
.....  
.....

18. If you come from far are, there other hospitals near where you live which offer occupational therapy services?

Yes [ ]

No [ ]

19. If Yes for the above what could have motivated you to bring your child this hospital?

Explain.....  
.....  
.....

20. If you are employed do you get time off from your employer to take your child to the hospital for each appointment?

No [ ]

Yes [ ]

21. If No for the above what arrangements have you made to ensure the child is given therapy?

Explain.....  
.....  
.....

**Communication between clinician and Patient**



22. Does the clinician explain to you about the condition of the child before carrying out therapy?

Yes [ ]

No [ ]

23. Does the clinician give you chance to talk about your problems?

Yes [ ]

No [ ]

24. Do you feel the clinician gives you enough information about about the treatment?

Yes [ ]

No [ ]

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

26. Are you satisfied with the treatment offered to your child in occupational therapy?

Yes [ ]

No [ ]

27. What is your comment on the way the clinician handles you and the child during

treatment?.....  
.....

**Social/Economic support**

28. Are you able to afford the cost of treatment each time you come?

Yes [ ]

No [ ]

29. Do you find it expensive to attend to treatment every week?

Yes [ ]

No [ ]

30. If the services are expensive who pays for them?

Childs mother [ ]

Child's father [ ]

Grandmother [ ]

Fund raising/ Friends [ ]

Others.....

**Transport**

31. How much do you pay for your transport to and from the hospital for each visit?.....  
.....

32. What do you use as the mode of transport?

.....  
.....

33. Is this transport convenient to you and the child?

Yes [ ]

No [ ]

34. If no for the above what problems do you encounter ?

explain.....  
.....

**Physical Support**

35. Do you have any problems in carrying your child to the hospital?

Yes[ ]

No [ ]

36. If Yes for the above explain the kind of problems you encounter

.....  
.....

37. Do you get any one to help you carry the child to the hospital?

Yes [ ]

No [ ]

38. If No for the above how do you manage to reach the hospital for each appointment?

Explain.....  
.....

39. Do you have anyone to leave the other children at home?

Yes [ ]

No [ ]

**Waiting time**

40. Do you find time to attend to the treatment?

Yes [ ]

No [ ]

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

	<b>Duration of waiting</b>	
1	Less than 30 minutes	
2	Greater than 30	
3	Approximately 1 hr.	
4	Approximately 2 hr.	
5	Approximately 3 hr.	

6	More than 3 hr.	
---	-----------------	--

42. Does time spend in the hospital affect your other programs?

Yes [ ]

No [ ]

Explain.....  
 .....

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

**Knowledge of cerebral palsy and importance of treatment**

44. Do you understand why you should attend treatment?

Yes [ ]

No [ ]

45. Did you know what cerebral palsy before you brought your child to occupational therapy?

Yes [ ]

No [ ]

46. At the time of diagnosing did the clinician explain to you what cerebral palsy is

Yes [ ]

No [ ]

47. Where you given clear instructions by the clinician on how to follow the prescribed treatment program?

Yes [ ]

No [ ]

48. Are you satisfied with the recovery process of your child?

Yes [ ]

No [ ]

## **SECTION B**

### **Interview Guide for Key Informants**

#### **Demographic Data**

Gender Male [ ] Female [ ]

Occupation.....

Address.....

**Main Questions**

1. How long have you been working at this Hospital? Please tick in the appropriate box

1-5 years [ ]

5-10 years [ ]

10-20 years [ ]

Over 20 years [ ]

2. What is the average number of cerebral palsy patients treated in occupational therapy out-patient per month?

2-5 [ ]

5-7 [ ]

7-10 [ ]

Over 10 [ ]

3. How many cerebral palsy patients are discharged from occupational therapy per month? Average of

1-3 [ ]

3-7 [ ]

None [ ]

5.If none in the above what could be the reason for this

.....  
.....

6. Does all the booked cerebral palsy patients turn up for their appointment on the right date? Yes [ ] No [ ]

7. If no for the above what do they say is the reason?

Explain.....  
.....

4. Have you noticed or heard some caregivers expressing difficulties or challenges in attending O.T services?

Yes [ ]

No [ ]

Explain.....  
.....

5. Do you experience patients defaulting or having irregular attendance to treatment?

Yes [ ]

No [ ]

6. What do they say are the reasons for default/ irregular attendance to O.T Services?

.....  
.....



7. What do you think are the reasons for the irregular attendance or defaulting?

Explain.....  
.....

8. Among the reasons above which ones do you think are the leading for the irregular compliance?

.....  
.....

9. What do you think are the factors that can make caregivers to comply with Occupational Therapy services regularly?

.....  
.....

10. Explain why each factor mentioned above is considered a motivating factor?

.....  
.....

11. How are the caregivers involved in the treatment of the child?

.....  
.....

12. Are the parents/caregivers given information on the diagnosis and management of the child before therapy begins?

Yes [ ]

No [ ]

13. Some caregivers don't seem to have a genuine reason for not attending O.T services regularly. What is your comment?

.....  
.....

14. Are all parents/caregivers of children with cerebral palsy able to pay for the child's treatment?

Yes [    ]

No [    ]

Some [    ]

15. If no or some in above who pays for their treatment?.....  
.....

16. What do they say about the cost of treatment?

Affordable [    ]

Expensive [    ]

Not sure [    ]

17. What time are patients booked for treatment?.....  
.....  
.....

18. What is the average time they have to wait before they are served?.....  
.....

19. What is the average waiting time for the patients?.....  
.....

20. Do you meet this time?

Yes [ ]

No [ ]

21. If no for above what could be the reason for this?

Explain.....  
.....  
.....

22. Do you experience any complaints from clients for delays in the queue?  
What do they say?

Explain.....  
.....

24. Do the parent/caregivers complain about their mode of transport?

What do they say?

Explain.....  
.....

25. Are the patients given information about the child's diagnosis and treatment on the first day they come for treatment?

Yes [ ]

No [ ]

27. What are their reactions to the condition of the child?

.....  
.....

28. How are parents/caregivers involved in the treatment of the child?.....

.....

29. Is there anything else that you want to add to what you have said?

.....  
.....

Thank you for your time and giving me honest answers. I promise to share the results of my findings

**APPENDIX III: Approval letter from the University of Nairobi**



UNIVERSITY OF NAIROBI  
COLLEGE OF EDUCATION AND EXTERNAL STUDIES  
SCHOOL OF CONTINUING AND DISTANCE EDUCATION  
DEPARTMENT OF EXTRA- MURAL STUDIES

Telegram: 'CEES'  
Telephone: KARURI 32117&32021  
Your Ref:

P.O BOX 30187, NAIROBI  
or P.O BOX 584 ELDORET  
KENYA

28<sup>TH</sup> MAY, 2014

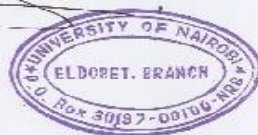
TO WHOM IT MAY CONCERN

SUBJECT: LOYCE CHEPKORIR BIWOIT L50/61238/2013

The above named is a student at the University of Nairobi, College of Education and External Studies, Department of Extra Mural Studies pursuing a course leading to the award of Masters of arts in Project Planning and Management. For this course to be complete, she is required to write and submit a research project. Therefore, the purposes of this letter is to kindly request you to accord her necessary assistance in getting information that will enable her complete the Research project. Her area of study is titled "factors influencing Cerebral Palsy Caregivers adherence to occupational therapy in Uasin Gishu County: case of Mui Teaching and Referral Hospital."

Thank you,

SAKAJA Y. M.  
CENTRE ORGANIZER  
ELDORET AND ENVIRONS



**APPENDIX IV: Approval letter from National Commission for Science  
Technology and Innovation**