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**"Community-Based Rehabilitation and Physiotherapy treatment of  
children with Cerebral palsy – Nairobi"**

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## **ABSTRACT**

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### **Title**

Community-Based Rehabilitation and Physiotherapy treatment of children with Cerebral palsy – Nairobi.

### **Background**

1978 the World Health Organization introduced a project called Community-Based Rehabilitation (CBR) with the purpose of improving quality of life amongst individuals with disorders in developing countries. In Kenya, physiotherapists mainly gain their knowledge about Cerebral Palsy (CP) through clinical experience. CP comprises different forms of non-progressive and non-reversible damages in the immature brain. Within Kenya, CP is very common since many women deliver at home without any medical care.

### **Aim**

The aim of this study was to describe the authors' and the physiotherapists' experiences of the Community-Based Rehabilitation organization, concerning physiotherapy treatment in habilitation of children with Cerebral Palsy.

### **Design**

Qualitative approach.

### **Methods**

The study was a two weeks observational study with a qualitative approach, where the authors mainly observed but also interviewed physiotherapists working within CBR during treatment of children with CP. Data analysis were inspired by manifest content analysis.

### **Results**

The community was provided with Urban CBR, where parents visited the center with their children and Rural CBR, where physiotherapists did home visits. One of the visited CBR centers was a children's home for physically and intellectually disabled children. The other visited CBR centers covered specific districts and received outpatients only. The CBR physiotherapists' priority assignments were to examine the children to be able to identify the main issue. According to this, short and long term achievements were defined and a treatment plan was compiled. Treatment strategies used were massage and contracture prevention. Also included was sitting, standing and walking exercises.

### **Discussion**

Despite supervision and studying articles concerning this method, it was arcane and ambiguous. During data analysis we may have lost important meaning units because of inexperience. It is fortunate that there are physiotherapists who are prepared to work within CBR, otherwise most children would not receive any treatment. The question is, whether the treatments are beneficial only or if there are also some unfavorable consequences' for the children. Literature claims that rough and hasty movements may cause more damage than advantages, counteracting the contracture prevention.

### **Key words**

Physical treatment, Physical disabilities, World Health Organization, Slum areas, Kenya.

## **SAMMANFATTNING**

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### **Titel**

"Community-Based Rehabilitation och Sjukgymnastisk behandling av barn med Cerebral Pares – Nairobi"

### **Bakgrund**

1978 introducerade World Health Organization projektet Community-Based Rehabilitation (CBR) som syftar till att förbättra livskvaliteten bland individer med funktionshinder i utvecklingsländer. Sjukgymnaster i Kenya får sin huvudsakliga kunskap om Cerebral Pares (CP) genom klinisk erfarenhet. Cerebral Pares omfattar olika former av regressiva och irreversibla skador i den omogna hjärnan. I Kenya är CP vanligt förekommande på grund av att många kvinnor föder hemma utan tillgång till sjukvård.

### **Syfte**

Syftet med studien var att beskriva författarnas och sjukgymnasternas upplevelse av organisationen kring Community-Based Rehabilitation med avseende på sjukgymnastisk behandling vid habilitering av barn med Cerebral Pares.

### **Studiedesign**

Kvalitativ ansats.

### **Metod**

Uppsatsen omfattade två veckors observationsstudier med en kvalitativ ansats, där författarna primärt observerade men även intervjuade sjukgymnaster inom CBR i samband med behandling av barn med Cerebral Pares. Analysmetoden inspirerades av manifest innehållsanalys.

### **Resultat**

Samhället var försett med Urban CBR, där föräldrar och barn besökte centrat samt Rural CBR, där sjukgymnasten gjorde hembesök. Ett av de besökta CBR-centren var ett barnhem för fysiskt och psykiskt funktionshindrade barn. De andra CBR-centren täckte specifika distrikt och hade endast mottagningsbesök. För att CBR-sjukgymnaster skulle kunna identifiera de primära problemen, undersöktes barnen och utifrån dessa fynd utformades en behandlingsplan med kort respektive långsiktiga mål.

Behandlingsmetoder som användes var massage och kontrakturprofylax. Även sitt-, stå- och gångträning inkluderas i den sjukgymnastiska behandlingen.

### **Diskussion**

Trots handledning och granskning av artiklar som berör denna metod, fann författarna den svårtolkad. Under dataanalysen kan viktiga meningsbärande enheter ha gått förlorade på grund av författarnas bristande erfarenhet. Det är tur att det finns sjukgymnaster som är beredda att arbeta inom CBR, då många barn annars inte skulle få någon behandling överhuvud taget, men ibland tedde sig behandlingen onödigt hårdhänt. Författarna ställer sig frågan huruvida all behandling är fördelaktig eller om den i vissa fall har negativa effekter.

### **Nyckelord**

Fysisk behandling, Fysiska funktionshinder, World Health Organization, Slumområden, Kenya.

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## **BACKGROUND**

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### **COMMUNITY-BASED REHABILITATION**

In 1978, the World Health Organization (WHO) introduced a project called Community-Based Rehabilitation (CBR) with purpose of improving quality of life amongst individuals with disorders, in developing countries (1).

Community-Based Rehabilitation is a strategy to ensure that conventions and laws, concerning human rights are followed. Today CBR is established in approximately 90 countries, but still there are 62 countries where rehabilitation is inaccessible for disabled individuals. Community contributions are used to make rehabilitation more accessible and also to increase acceptance in the community (1)

According to WHO recommendations, a suitable member of the community is assigned and educated to be able to supervise and guide people in their surrounding (2). Community-Based Rehabilitation puts main focus on empowerment (1). Therefore the supervisors are obliged to put effort into enabling individuals with disabilities to participate more in activities in their community. For example, they have to arrange for children to attend school and give grownups with functional disabilities an increased possibility to get an appropriate occupation (2).

WHO composed an extensive manual for CBR, 1989, which hold definitions of functional and intellectual disabilities and a description of what various obstacles and needs these disabilities may imply. There are specific self-help chapters in the manual, directed to the individual and informative chapters for the family or the local supervisor. The manual contains conformed training packages with simple and accessible illustrations and thorough instructions of how to carry out activities of daily living. There are chapters concerning; hearing impairments, speech impediment, intellectual disabilities, functional disabilities and a chapter for individuals with multiple disabilities etc. There are different coping strategies to handle for example; locomotion techniques, how to create homemade devices, suitable resting positions, decubitus prevention, contracture prevention and use of orthosis (2).

In 2010, information and material collected from published articles and CBR wielders from all over the world was compiled into a document; "Community-Based Rehabilitation, CBR guidelines". Amongst many others, several Kenyan organizations for disabled individuals for example Association for the Physically Disabled in Kenya (APDK) and Kenya Medical Training College (KMTC) were involved in the elaboration (1).

### **PHYSIOTHERAPY WITHIN KENYA**

#### ***Education***

Kenya Medical Training College (KMTC), one of the largest colleges in East- and Central Africa, educates physiotherapists, nurses and pharmacists amongst other professionals. Cooperation between KMTC and CBR gives students the opportunity to acquire clinical experience by practicing their skills together with experienced physiotherapists (3). A diploma in physiotherapy is the result of three years of studying at KMTC. To attain a Master's degree it is necessary to study abroad since there are no educations available, for specializing in a subject, within Kenya. Knowledge about CP is gained through the rehabilitation course during the physiotherapy education and further through clinical

experience. Employees within CBR are given the opportunity to participate in supplementary training courses arranged by African Medical Resource Organization. A physiotherapist in Kenya is considered an expert in a subject after five years of clinical experience [*Personal communication with physiotherapist 2010-09-14*].

### ***Career***

Physiotherapists employed by CBR can work either within the organization exclusively or with an additional employment at government hospitals. Only a few physiotherapists work five days a week at the same CBR center. It is more common to work within different CBR centers and government hospitals. There are also physiotherapists who work with Kenya international athletic teams, and travelling abroad is a considerable part of their duties. The government, who pay the physiotherapist's salary, is responsible to find a substitute employee when the physiotherapist is on an international assignment [*Personal communication with physiotherapist 2010-09-14*].

### **CEREBRAL PALSY**

Cerebral Palsy (CP) comprises different forms of non-progressive and non-reversible damages in the immature brain during the fetal development and before two years of age (4). Brain damage is often caused by infections, circulatory disorders, hemorrhage or cerebral anoxia. Motor skill acquisition and postural control is generally affected, but symptoms and level of limitations in activity and participation differs from one child to another, depending on where the injury is located. Children with CP generally have a lower physical capacity in comparison to children of the same age without functional disorders. Affected functions such as reduced cognition, sensibility, communication and perception also affect the degree of activity and thereby the participation. CP is a term that includes three categories; spastic CP, dyskinetic CP, and ataxic CP (5).

Spastic CP is the largest main group which is characterized by reduced skeletal muscle control, abnormal muscle tonus, increased reflexes and spasms. Spastic CP includes hemiplegia (unilateral paralysis where one side of the body is affected), diplegia (bilateral paralysis where the upper or lower extremity is affected) and tetraplegia (multilateral paralysis, where both upper and lower extremity are affected) (5).

In dyskinetic CP the basal ganglia, which coordinate movements and muscle tonus, are damaged. Symptoms are involuntary and twisted movements and/or spasms and do not correspond to the pattern amongst individuals without this disability (6).

Ataxic CP is caused by a defect in the cerebellum which results in difficulties controlling skeletal muscle coordination (5).

### ***Cerebral Palsy in Kenya***

Within Kenya, CP is very common since many women deliver at home without medical care. If more women delivered at the hospitals it would be possible to discover and prevent cases of CP to a greater extent. No official records, concerning the prevalence, seem to be available. The physiotherapists believe that out of the children, known to the hospitals, two or three children are diagnosed out of a hundred born children. These numbers, however, are not official. Most cases of CP are caused by prolonged or complicated deliveries. Severe CP is often caused by exposure to pneumonia or other



infections. Children who have been diagnosed with CP are offered a six month checkup at one of the hospitals [*Personal communication with physiotherapist 2010-09-14*].

Many children have additional diagnosis such as epilepsy. Compared to the normal weight curve, many children with CP are underweight and therefore regularly examined at a health care institution. These children tend to have a very sensitive, soft skeleton and a weak lower back. Therefore it is important to be careful during physiotherapy to avoid causing fractures [*Personal communication with physiotherapist 2010-09-13*].

### ***Locating children with Cerebral Palsy***

Most children with CP are located at hospitals or Maternal Child Health delivery wards. Others are brought to the centers by their parents or located when CBR arrange camps with free exams and treatments. The sooner the children are given medical care, the better, but a lot of mothers bring their children for examination when they are approximately two years old. At this age it is noticeable if the child is not able to walk or manage activities other two year olds do [*Personal communication with physiotherapist 2010-09-14*].

### ***Social situation in families with disabled children***

Children with disabilities require a lot of additional expenses and are also very time consuming. For this reason many parents have to stay at home. The mothers stay at home to care for their children while the fathers have to provide for their families. Free medical care is provided for all children under the age of five, but henceforth the parents have to pay full price. Because of their financial situation they choose to visit the CBR centers where only a symbolic amount is paid. Some parents are funded by foreign donors to be able to pay school fees [*Personal communication with physiotherapist 2010-09-13*].

## **AIM OF STUDY**

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The aim of this study was to describe the authors' and the physiotherapists' experiences of the Community-Based Rehabilitation organization, concerning physiotherapy treatment in habilitation of children with Cerebral Palsy.

## **OBJECTIVES**

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1. Which are the authors' experiences concerning treatment facilities and surroundings of the Community-Based Rehabilitation centers?
2. What are the physiotherapists perspectives concerning their assignments?
3. Which are the authors' experiences of the physiotherapists' work ethic and interaction with the children and relatives?
4. What are the physiotherapists perspectives concerning physiotherapy treatment of children with Cerebral Palsy?
5. What are the authors perspectives concerning physiotherapy treatment of children with Cerebral Palsy?

## **PARTICIPANTS**

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Five physiotherapists were observed and/or interviewed. The physiotherapists were educated at KMTC and had at least 15 years of working experience. The experience of working within CBR was an average of 7 years.

Nine children with CP were treated during the observations at three different centers. The observed children were between 6 months and 8 years old, with mild to severe CP and a various degree of physical and intellectual disabilities. Two cases were mild, four were moderate and three were severe. The patients with severe CP were small and underweight for their age. Not all of the children were affected intellectually but normally talented with physical disabilities only. Level of speech and ability to understand varied from child to child. Two of them were able to communicate independently, while others could not communicate at all. Two of the children were not aware of their surroundings and did not react to pain the way the other children did. These children were calm and only whimpered or made facial expressions. Six children had flexor spasticity and two had extensor spasticity. Four of the children observed were able to sit on their own with a little or no support. The other children were not able to control and stabilize head or trunk. At least four of the children were troubled by contractures and a lot of secretion. A few patients showed involuntary twitches in the whole body. One child had tense muscles on one side of the neck. A few children suffered from seizures, triggered by heat or fever. According to the physiotherapists the seizures were not epilepsy.

The main causes of CP, amongst the observed children, were complications during delivery or infections shortly after birth. Before the children were diagnosed with CP, mostly at more advanced clinics, many of the parents had to visit several doctors. None of the children were first time visitors. Some of them had received physiotherapy for several years, either at hospitals, within CBR or both, while others had not received any treatment before they came in contact with CBR.

The mothers, the orthopedic technicians and the occupational therapists were indirectly observed during treatment, when interacting with the children or the physiotherapists.

### **Inclusions**

- Physiotherapists, within Nairobi, employed within Community-Based Rehabilitation.
- Children aged 0-10, with mild to severe Cerebral Palsy.

### **Exclusions**

- Physiotherapists without experience of children with Cerebral Palsy.
- Children where Cerebral Palsy is not included in the disabilities.
- Children without physical disabilities.

## **METHODS**

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The study was a two weeks observational study with a qualitative approach, based in Nairobi, Kenya, where the authors mainly observed, but also interviewed, physiotherapists working within CBR and children with CP.

### ***Data were collected in the following situations:***

- Direct observations of the treatment facilities and surroundings of CBR centers.
- Direct observations of treatment situations.
- Interviews with the physiotherapists.

The prime observations were of the treatment process but the authors also observed the context of CBR facilities and surroundings. The authors choose this method in order to acquire a deeper understanding considering the aim of this study.

### ***Data collection measures:***

- Notes were taken during all observations and interviews.
- Video camera was used during treatment situations.
- Dictaphone was used during interviews with the physiotherapists.

Kenya Medical Training College arranged transport to the CBR centers and introduced the authors to the participants. The physiotherapists had already agreed to participate in advance, while parents were informed about this study, before treatment and asked permission to let their children participate. No parents declined participation.

Initially the physiotherapists and the children were observed during treatment and the authors were positioned next to the physiotherapists; documenting, using a video camera and taking notes. The authors occasionally asked questions and the physiotherapists spoke freely during treatment which was included in the documentation material.

After treatment the physiotherapists were interviewed separately and only the authors were present in the room where the interviews took place. One of the authors lead the interview by asking the questions while the other one took notes and recorded, using the Dictaphone. The interviews were half structured and held in English. The physiotherapists were encouraged to speak freely.

The different data collection measures were used to study the treatment strategies and interactions between physiotherapists and children with CP. The different sources of information were triangulated, to facilitate a broad understanding of the treatment of CP in CBR within Nairobi's slum areas (7).

After each visit at the CBR-centers the authors wrote their handwritten notes from observations and interviews on a computer. Also valuable material from the video camera was put into writing.

### ***Data analysis***

In the analytic phase, text, notes and sound sequences were compiled literally and read thoroughly. Meaning units were coded in different colors using fluorescent pens. Each

code was then classified into appropriate categories with sub-categories. To organize the collected data and make it more accessible, the categories were put into themes which answered and described the aim of this study. Data analysis was inspired by manifest content analysis (8).

### ***Ethics***

The material was treated confidentially and the approval from each participant was requested. The “ethics committee of the department of health sciences” was consulted for ethical advises.

## **RESULT**

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### **COMMUNITY-BASED REHABILITATION CENTERS**

During this observational study, three CBR centers were visited. Poor infrastructure made it impossible to reach some of the slum areas by car and the only way to get to the centers was by foot. The centers were enclosed by a stench of exhaust gases and further into the slum it smelled like a hog-pen. The roads were made out of stamped dirt, mud and the remains of old garbage. People were well dressed, wearing costumes and proper dresses, in contrast to their bad conditioned homes and stores (*Observation*).

The visited CBR centers were small, crowded buildings with tin roofs, situated behind tall walls lined with barbed wire or hidden in groves. Despite cold weather, children were treated with doors kept wide open and only bars covering the window frames. Parents and children were seated on plastic chairs along the walls waiting for treatment. Only curtains separated treatment areas from waiting halls (*Observation*).

One of the visited CBR centers was a children’s home, sponsored by surrounding communities, for physically and intellectually disabled children. There were also children without disabilities who had either lost their parents or children from poor families. The disabled children were divided into four different groups; completely dependent, partly independent, in need of minimal assistance and completely physically independent, but with some intellectual disabilities (*Observation and interview*).

The children’s home was divided into different departments; a teaching department, where children with disabilities were educated. A day nursery department for the younger children who lived at the center, where also children from the nearby community were welcome to attend. A caretaking department, where all social needs of infants and other dependent children were taken care of and a nursing department with one nurse employed who was responsible for the medical care. There was also a rehabilitation department where physiotherapists cooperated with occupational therapists. At the rehabilitation department both residents and outpatients were treated. Disabled children received approximately thirty minutes of treatment each day. Except from when these children were treated, washed or fed they spent most of the morning sitting in a room together with a caretaker. After lunch, the most disabled children were put to bed for the rest of the day, while the other children went back to class. Children who were in need of physiotherapy, besides the severely disabled ones, were treated during the afternoon. The center was manned twenty-four seven. During holidays the orphans stayed at the center while the other children visited their families. Unfortunately, most parents were not interested in their children’s’ treatment.

Therefore, after holidays, they tend to return to the center in a worse state than when they left. A few parents had shown an actual interest in performing home treatment and were able to maintain the child's abilities during the holidays (*Interview*).

The other visited CBR centers covered specific districts and received outpatients only. These centers were open once or twice a week. Most of the patients were either diagnosed with or had indications of CP. The remaining children had other physical or intellectual disabilities. These centers were manned by physiotherapists, occupational therapists, social workers and orthopedic technicians. In charge of the centers was a coordinator (*Interview*).

### ***Treatment facilities***

The facilities and its interior design were old and worn. The centers were supplied with both home- and factory-made equipment of a varying standard. There were walking tables, trampolines, manual lifts, parallel bars, standing tables, standing boards, walking frames, bunk beds, mattresses, Bobath balls, physio rolls, weight cuffs, stationary bikes, crutches, metal leg braces, some toys etc (*Observation*).

The treatment areas were crowded and it was difficult not to get in anyone's way. While the physiotherapist treated one child, another one was dressed and a third one was undressed for treatment, all of them on the same bunk bed. Mothers changed diapers on their children before treatment, using the bunk bed as a changing table. Next to the bunk bed, there was another child on an exercise bike. Children were constantly running in and out of the treatment rooms. The volume during treatment was deafening, but no one else seemed to care and no one was using hearing protection. One of the physiotherapists explained that "*I don't use anything to protect my ears because I am so used to the children crying*". The bunk beds were covered in sheets, but these were not changed in between patients. No one used gloves or washed their hands in between patients. One of the occupational therapists brought soap and a bucket of hot water, when all treatments were finished. This was the first time that anyone of the therapists washed their hands (*Observation and interview*).

### **PHYSIOTHERAPIST ASSIGNMENTS**

The CBR physiotherapists' priority assignments are to examine and assess the children as early as possible. The children are then referred to the nearest Health care center, where a doctor would be available to diagnose and categorize, due to their functional abilities. Thereafter it is decided which CBR institution would be best suited for the children. Most children are referred to the nearest regular CBR center (*Interview*).

Parents, who are not able or willing to take care of their disabled children are advised whether it is appropriate to put their children in a CBR children's home or not, depending on the children's needs. Children are only allowed to a CBR's children's home if the staff found it the most beneficial alternative for them. Children are also referred to other institutions when a CBR center is unable to fulfill their needs (*Interview*).

According to one of the physiotherapists there were not nearly enough physiotherapists employed by CBR. Usually there would be only one working at each center and the only cooperation they had with other physiotherapists was the referral of patients between centers or clinics (*Interview*).

The community is provided with Urban CBR, where parents visit the center with their children and Rural CBR, where physiotherapists, in some cases, visit the family at home. The physiotherapists explained that, when children reach an age of five, in cases where it was need, a speech trainer is included in the treatment. This is also the age when further assessment was carried out in purpose to give the children opportunity to attend school. A psychiatrist classifies the children's intellectual level in order to put them in suitable grades. Intellectually stable children are rehabilitated within CBR until they reach an age of ten and then most children are sent to appropriate boarding schools where they have access to a physiotherapist (*Interview*).

### ***Education and information to families and community***

It is still a common belief, amongst people of Kenya, that disabilities are contagious or considered a bad omen. Therefore, physiotherapists within CBR, find it very important to educate the community about intellectual and functional disabilities. A vital part of their jobs is to prevent stigmatization by integrating disabled children into the community. In Nairobi, CBR put a lot of effort into creating a more understanding and supportive surrounding by informing neighbors, who live extremely close together, about the needs of disabled children. One of the physiotherapists explained that; *"This creates a mutual respect and makes it possible for families to, for example, keeps the child's space consuming aids outside their crowded homes."* (*Interview*)

Most parents who visit the CBR centers have high expectations and believe that the physiotherapists will cure their children within three treatments. They are determined to have their children walking and acting like contemporaries. Therefore it is important to create awareness amongst parents, that treatment takes time and emphasize the importance of sub targets leading towards the main goal. The regime in treatment of CP, within CBR, is to educate the children and their parents, to make sure the children are provided with continuous treatment. All parents who visit the centers are taught simple and safe exercises that they could carry out at home. They are also provided with as much information, about their children's special needs, as possible (*Interview*).

One of the physiotherapist mentions the network of parents, developed by CBR, where the parents are educated in purpose to be able to identify children with disabilities at an early stage. These parents are supposed to supervise other parents and advise them when they ought to bring their children to a CBR center. Three times a year workshops are arranged, where only parents are invited. This is an opportunity for new parents to integrate with parents who had visited the centers for years. They are able to share their experiences and many parents found comfort in knowing that there are other families who carry the same burden as they do. The parents are taught about the background of CP and how to identify the most common symptoms. They learn about nutrition, hygiene, how to avoid bedsores and also how to prevent contractures. Another important aspect of the workshops is that the parents got their questions answered by medical staff (*Interview*).

### ***Prescription of aids***

Another important physiotherapist assignment is to prescribe necessary aids. Home visits are often necessary to be able to plan and decide individual solutions and what aids would be appropriate. The physiotherapists cooperate with orthopedic technicians

to acquire correct measurements before manufacturing or ordering equipments. In most cases a carpenter is hired to design the aid (*Interview*).

### **WORK ETHIC AND INTERACTION**

The physiotherapists found it very important, when working with children, to involve the parents in the treatment and motivate the children. One physiotherapist claimed that; *"It is important that the children know that they have parents and that the parents acknowledge their children's disabilities."* (*Interview*)

Most children screamed loudly and constantly to a point where they seemed to lose their breath during treatment which seemed to stimulate a lot of coughing and mobilization of secretion. After physiotherapy most of the children seemed to be exhausted. None of the parents or medical staff asked the children about their experience of the treatment (*Observation*).

The children were occasionally encouraged and comforted by their mothers, during treatment, but most of the time the crying was ignored. The mothers and the physiotherapists commanded and repeatedly slapped the children to make them stop crying while the treatment continued. During the exercise where the children were tied to standing boards, the mothers kept them company and encouraged them to work on their posture (*Observations*).

During observations the cell phone was answered repeatedly. The explanation was that the mothers got nervous and scared if the medical staff at CBR did not act natural and relaxed around them. Since their husbands would answer the phone, the physiotherapists did the same. One of the physiotherapists also explained that *"A light slap, every now and then, is also something that the children recognize. It is very important to make them feel at home. The mothers are also rather tough on their children."* The physiotherapists chatted a lot with the mothers during treatment, but did not talk a lot to the children, other than when they occasionally encouraged or reprimanded them. One of the physiotherapists claimed that it was important to be stern with the children, because they were not able to understand simple conversations. The physiotherapist talked a lot to the parents about anything from politics to more private subjects to make them feel more relaxed. In return, they were more open and prone to tell the physiotherapists about things that had happened at home, for example if the child had fallen (*Observation and interview*).

One of the physiotherapists tried to calm upset children by giving toys and swinging them forth and back in the standing table. While this physiotherapist was busy treating another patient, the child in the standing table was occasionally paid attention. For instance, the physiotherapist wiped the children around their mouths frequently and tied shawls around their necks to avoid saliva dripping on their clothes (*Observation*).

Other CBR staffs interacted with the children as well. One of the orthopedic technicians was joking around with the children. An occupational therapist helped out in changing one of the patient's clothes another one took a photo of one of the crying children, with a digital camera, and showed the photo to the child (*Observation*).

## **PHYSIOTHERAPY TREATMENT OF CHILDREN WITH CEREBRAL PALSY**

Regular physiotherapy treatments lasted thirty minutes because the children tended to lose focus and not manage to participate any longer. One physiotherapist explained; *"The effect of the treatment is lost when the child is too tired to cooperate."* When the children had had enough, they showed their discomfort by twisting and squirming, trying to avoid the treatment. At first, the physiotherapists examined the children, to be able to identify the main issue. According to this, short and long term achievements were defined and a treatment plan was compiled. Most parents' first priority was to teach their children how to walk and communicate. The physiotherapists' contribution, to enable this, was to stimulate muscles and prevent contractures during treatment (*Observation and interview*).

One of the physiotherapists' claimed that; *"A holistic perspective is always applied, in treatment of children with CP."* The first priority was to make sure that the children were able to control head and trunk to enable a sitting position. This in comparison to, for example, knee injuries where the physiotherapists' would focus on the knee exclusively (*Interview*).

### ***Massage***

Massage, with olive oil or Vaseline, was used to heat the muscles. The physiotherapists used effleurage and frictions to stimulate the trunk musculature. Most of the children got this kind of back massage, with main focus on the Erector Spinae muscles. Occasionally, during massage, the physiotherapists put pressure over the spine. The physiotherapists avoided massaging patients with increased muscle tonus and spasticity. In these cases a slow stretching of the muscles were used instead, while muscles that were not spastic were treated with fast movements in purpose to stimulate the musculature (*Observation and interview*).

### ***Contracture prevention***

All children were treated with contracture prevention. The physiotherapists worked through almost all of the joints, beginning with the upper limb, in most cases. The physiotherapists all used a similar technique, but they used different structures during treatment. One of the physiotherapists finished one limb at a time. The contracture prevention was performed, starting distally and moving proximally. Another physiotherapist started the treatment, sometimes in the upper limb, other times in the lower limb, switching between sides and limbs in an unclear pattern. Most joints were manually hyper extended. The children were sometimes lifted by one arm or one leg when changing positions during treatment (*Observation*).

### ***Contracture prevention of the upper limb***

Generally, the physiotherapists started with contracture prevention of all finger joints, concentrating especially on the thumb. The palm was massaged and traction of the proximal finger joints was performed. The physiotherapists battered the children's palms and one of them explained that; *"The purpose is to massage the joints and to fatigue the stretch reflexes."* In combined movements, which resemble a rotation of the wrist, the physiotherapists performed dorsal and palmar flexion, radial and ulnar deviation. Thereafter the elbow joint was flexed, extended and turned into supination and pronation. The physiotherapists performed abduction, adduction and rotation of the shoulder. In many cases, the treatment was not symmetrical. Sometimes contracture



prevention was performed repeatedly in a specific joint, but not bilaterally. Most movements were combined and no motions were performed in the sagittal, frontal and transversal plane exclusively (*Observation and interview*).

### ***Contracture prevention of the trunk***

One of the children had stiff neck musculature and was treated initially with massage of the neck. The neck was then twisted and pressure was put on the forehead in purpose to stretch the musculature. This treatment was performed bilaterally. The physiotherapist stimulated the trunk by wiping it with a cloth. With the child in a sitting position, the physiotherapist massaged and put pressure between scapulae, while the shoulders were pulled back. The trunk was rotated with the child in a dorsal position. The child was then placed in the physiotherapist's lap, in a sitting position and the trunk was flexed and rotated once again (*Observation*).

The physiotherapist then stood up. In purpose to strengthen the trunk musculature and improve the posture by activating the back muscles an exercise was used where the child was put into a standing position, with the feet against the physiotherapist's legs with support around the pelvis. The child was leaned slightly forward in this position, facing the floor, to stimulate activation of the back musculature. The extension of the trunk was performed by the physiotherapist, while the child was commanded to extend the upper body. Then the physiotherapist let go of the upper body and the child had to work eccentric, decelerating the flexion. The same exercise was performed with the child hanging over the edge of a bunk bed, in a ventral position. The child was then turned into a dorsal position, still with the trunk hanging over the side of the bunk bed. The physiotherapist pulled the child by one arm, into a trunk flexion and let the child decelerate the extension of the trunk. Next, the physiotherapist held the child sideways with the child's back against the own trunk. In this position the trunk was bent into extension repeatedly (*Observation and interview*).

With the child in a sitting position and the legs straightened, the mother or an occupational therapist put pressure over the knee joints to keep them fully extended. The physiotherapist repeatedly rotated, and then swung the trunk roughly into flexion, holding a stern grip around the child's neck, without any other support of the back (*Observation and interview*).

### ***Contracture prevention of the lower limb***

The physiotherapist massaged the legs and performed hasty stretching of the musculature in the lower limb. The physiotherapist rapidly switched from knee extension to knee flexion, rotation of the hip and rapid dorsi flexion. These movements were performed fast and the knees were never held in a fully flexed or extended position (*Observation*).

With the child in a ventral position, the physiotherapist flexed the child's knees to ninety degrees and hit the sole of the feet with clenched fists, concentrating on the heels. The body was partly lifted from the bunk bed when the hip joints were roughly extended. Thereafter the child was put into a sitting position with the hips, knees and feet fully flexed, bilaterally. With a firm grip around the child's ankles, the physiotherapist pressed the feet against the child's bottom, using the child's weight and then explained that; "*Many of the children have shortened Achilles tendons which is why they need to be*

*stretched" (Observation and interview).*

With the child in a dorsal position, the legs were forced into abduction. Thereafter hip joints were bilaterally rotated and extended with the knees flexed. Pronation, supination and hyperextension of the feet were performed with the child in a dorsal position. The child suffered from clonus. The physiotherapist put one hand against the sole of the foot and the other hand around the child's ankle (*Observation and interview*).

The child was put into a standing position and the physiotherapist lifted the child approximately fifteen centimeters, before letting go of the child who hit the bunk bed with the soles of the feet. The mother assisted by correcting the standing position. The physiotherapist claimed that; "*The purpose of this exercise is to stimulate the proprioception" (Observation and interview).*

### ***Activity of Daily Living exercises***

Activity of Daily Living (ADL) exercises were included in physiotherapy treatment when it was possible. The physiotherapist took into consideration, the children's abilities and interests. "*I let one of the older children sweep the floors during treatment, with some supervision, because she enjoys it." (Interview)*

### ***Sitting exercises***

When sitting exercises were applied, the purpose was to enable the children to sit without support, lasting from five to thirty minutes depending on the children's stamina. In cases where children had difficulties sitting, CBR sometimes offered specially designed chairs. In cases where children spent most of the day in a sitting position, sitting exercises were excluded (*Interview*).

### ***Standing exercises***

Since many children spent most of their day in a sitting position, it was very important to include standing exercises during treatment. The children were usually tied to a standing table for twenty to thirty minutes. The physiotherapists started treating the next patient, while the previous child was still tied to the standing table. When a patient was not able to stand properly, because of a club foot, the physiotherapists tried to straighten and stabilize the standing position by putting pieces of cloth underneath the foot (*Observation and interview*).

To be able to tie one of the older children to a standing board, the physiotherapist had to get assistance from one of the occupational therapists and the child's mother. To stabilize the child, pieces of cloth were tied over the knees, the pelvis and also over the trunk, beneath the axillas. A mirror was sometimes put in front of the child in purpose for the child to be able to observe and correct the own position and posture during standing exercises (*Observation and interview*).

### ***Walking exercises***

It was important, if possible, to teach a child to walk, partly because it was required by society and the family, but also in purpose to avoid osteoporosis. Children, who could not walk were tied to a standing board during treatment, but it was preferable if they were able to walk, with or without devices. During walking exercises, one of the physiotherapists put one of the children in a walking table without harness, but the child

refused to stand up. In an attempt to convince the child to stand, the physiotherapist battered the back, but without result. To achieve a slower and more controlled gait amongst children who had a compensating walking strategy, the physiotherapists corrected the children by putting weight cuffs around the ankles (*Observation and interview*).

### ***Physio roll and Bobath ball***

Physio rolls, in different sizes, were used in treatment of smaller children, while Bobath balls were used for the older ones. Children, where seizures could be triggered, were not treated on the ball or physio roll. One of the physiotherapists put a child on a physio roll in a ventral position and swung the child back and forth, holding one hand in the lower back and one around the ankles. The mother held and stretched the child's arms forward. The physiotherapist stood behind the child, holding the feet while pushing and pulling forth and back. The knee joints were then rapidly extended. The child was put in a sitting position on the roll with one leg on each side and the physiotherapist stretched the trunk sideways, by swaying the child from side to side. The exercise was repeated with the child leaning forward over the roll, while the physiotherapist supported the back with one hand (*Observation and interview*).

One of the older observed children was put on a Bobath ball in a dorsal position. The shoulders, the pelvis and the trunk were pressed against the ball. The physiotherapist turned the child into a ventral position, lifting the child by one arm and one leg. Alternating the right and the left leg, the hips were pulled into extension and then both legs at the same time (*Observation*).

### ***Preventing fear of falling***

One of the observed children was lifted by one arm and was then turned up-side down. The physiotherapist held the child by the wrists, while swinging back and forth. The child was held still for a moment and then rotated, still in an up-side-down position. The physiotherapist explained that; "*I do this to reduce the child's fear of falling.*" The child was then held by the left arm and the left leg. The physiotherapist swung the child from the bunk bed, forth and back in a semicircle. Thereafter, the child was put into a piece of cloth, and together with the mother, the physiotherapist created a hammock where they swung the child forth and back. The physiotherapist then lifted the child by the arms and tried to make the child stand up. The child responded by flexing knees and hips. The physiotherapist started shaking the child by the arms, but the child kept resisting (*Observation and interview*).

### ***Orthosis***

Night orthosis were often used in purpose to prevent or reduce flexor spasticity and contractures, especially drop feet. Unfortunately it was expensive and therefore it was often difficult to offer the patients individually adjusted orthosis (*Interview*).

### ***Reflex stimulation***

A cloth was used to wipe the mouth, in purpose to get rid of secretions and also to stimulate the speech by activating the swallow reflex (*Observation and interview*).

## **DISCUSSION**

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The aim of this study was to describe the authors' and the physiotherapists' experiences of the Community-Based Rehabilitation organization, concerning physiotherapy treatment in habilitation of children with Cerebral Palsy.

### **Participants**

In purpose to de-identify the participants concerned, the authors chose not to reveal the number of physiotherapists observed in treatment situations.

It was more difficult, than expected, to find enough participants, especially physiotherapists employed by CBR. An explanation could have been low interest to participate amongst physiotherapists within CBR. Another reason could have been difficulties in arrangement of suitable transportation and appointments for the visits.

Since the opportunity to perform the observations and interviews were arranged by KMTC, the authors had limited control, concerning the selection of participants. On the other hand there might not have been an opportunity to establish the contact at all without the influence of KMTC.

Only nine patients were observed, but the authors did not find additional observations necessary. Observing children in a wide variety of ages, functional and intellectual abilities provide the reader with a versatile picture.

### **Methods**

Despite supervision and studying articles concerning this method, the authors found it arcane and ambiguous.

The main focus was to observe the participants, but it was difficult to separate observations from what the physiotherapist told us, during treatment, without losing the context. As a supplement to the observations, the authors used half structured interviews where the physiotherapists might have interpreted the questions differently. No interpreter was considered needed, because all medical staff and mothers spoke English fluently, which made it possible to ask if something was unclear. Considering that English was not the native language of neither Sweden nor Kenya, there might be some misunderstandings in the script. This in addition to the differences in cultures may have caused a lack of nuances in communication and therefore created additional misunderstandings. The reason why the authors chose to write the essay in English, was to enable the participants to read the completed essay.

The authors took precautions by documenting observations both with a video camera and by taking notes. During interviews a Dictaphone was used and notes were taken. Unfortunately the audio quality was inadequate and therefore worthless, but fortunately, the pictorial material from the video camera was useful and the notes were comprehensive and detailed. Because of government regulations the authors were advised not to take any photographs. Even though the physiotherapists assured that it was alright to film the children during treatments precautions were taken by asking each mother's permission separately.

During data analysis the authors may have lost important meaning units because of inexperience. Another more experienced author may have analyzed the text differently, using other categories and themes.

### **Result**

The result of this study may be affected by several human factors. For example, the author's interpretation may be influenced by their culture. Vocal expressions and body language could have been misunderstood. Someone who is familiar with the culture and has more experience of qualitative studies may have had a different result.

Only three centers were visited, but according to the author's opinion, an obvious distinction between all three of them makes them fairly representative.

According to the authors the secrecy at all centers were questionable. The medical records were kept in paper files on shelves, where unauthorized may easily get hold of them. This could be one of many cultural differences. The secrecy may not be as important in Nairobi as in Sweden or was this due to limited resources? Also the lack of privacy during treatment, where all patients, relatives and medical staff were situated in the same area seemed inappropriate according to the authors' personal opinions.

The observed physiotherapists did not use any gloves and did not wash their hands in between patients. The bunk beds were not cleaned or sheets changed. Once again, this could be due to cultural differences or because of limited access of water.

Devices were available, even though many of them were old and worn. The visited centers seemed generous in providing the children with appropriate aids. If an aid was not available the physiotherapists tried to make sure that an orthopedic technician designed it together with a carpenter. Even though there were not nearly enough financial resources, the staff seemed to work hard to fulfill the children and their parents' needs. According to CBR-manuals devices can easily be manufactured from common material that you would find in most homes (2). The authors unfortunately never confirmed that these CBR-manuals were available to the families.

All physiotherapists in this study worked hard to integrate children with disabilities in the community and put a lot of effort into decreasing stigmatization. The authors found this commitment impressive and continuous engagement would be of importance. The increased acceptance in the visited areas, established that physiotherapists were considered authorities who were able to influence the situation for children with disabilities.

Parents were involved in the treatment which implies that the physiotherapists' tried to motivate the parents to maintain the children's state and perform exercises at home until the next visit. The interaction, during treatment, between mothers and physiotherapists seemed friendly and relaxed, even though the physiotherapist occasionally slapped the crying children. According to the physiotherapist this was generally accepted in the society which was hard to accept for the authors who found this very unprofessional. During treatment the physiotherapists made some effort to comfort the children but most of the time they seemed to ignore communication and they seemed to constantly exceed the children's pain threshold. This was the authors'

experiences, and it might not have been as severe as it seemed. Still literature emphasizes the importance of supervision and a lot of verbal support during treatment of children with disabilities (9). The authors speculated whether this lack of communication and motivation affected the results of treatment negatively. This was yet another example of the cultural differences.

The observed physiotherapists' spoke of the importance of individualized treatments, but our interpretation was that they did not put this into practice. In physiotherapy treatment of children with CP, in Sweden, it is always taken into consideration the child's body function/structure, activity and participation to find suitable goals and thereby establish an individual treatment (10). The physiotherapists' treated all patients almost the same way with massage, contracture prevention and standing exercises. One of the physiotherapists' seemed to skip back and forth from one limb to another and the authors could not decide whether it was on purpose or if the physiotherapist was just being inconsequential. It was also interesting how the physiotherapists started with the smaller muscle groups and performed the trunk rotations last, which is the opposite of what the authors have been taught during the physiotherapy education at Lund University. These statements were also confirmed by studies, where it was verified that a generalized reduction of spasticity, with for example trunk rotations, may increase the range of motions. (11).

In all observed treatments standing exercises were included. According to literature, standing exercises, in purpose to achieve long-term stretching, may decrease spasticity temporarily in the lower limb (12). Most children had access to this treatment once a week only. Therefore the authors questioned the effects of the treatment.

During contracture prevention the children's joints were pushed into extreme and painful positions. There are studies concluding that there is moderate to high quality evidence, of stretching not being effective in treatment and prevention of contractures if it is not performed regularly for more than seven months (13). Therefore the authors find it questionable whether the contracture prevention, performed at children who are treated once a week by a physiotherapist, have positive effects.

Literature concerning treatment of CP, claims that the purpose of physiotherapy treatment should be to help the children become as independent and socially adapted as possible. One of the physiotherapists seemed to practice this philosophy by using ADL exercises during treatment which, according to several studies, have positive effects for the child's functioning in daily living. The treatment, in Sweden, is not supposed to normalize children with CP, while in Kenya, the aim in all cases were to teach the children to walk (10).

Treating fear of falling by holding a child upside down seemed unethical and according to the authors it ought to antagonize the purpose. It is seemed more likely that the treatment would traumatize the child and affect the trust between child and physiotherapist in future treatment. The authors found no evidence of this treatment being valid or reliable.

It was interesting how the physiotherapists in Kenya talked about rehabilitation of children with CP, while in Sweden the expression habilitation is used. Was this a mistake

or was it because they, to a greater extent, believed in normalizing the children? Association for the Physically Disabled in Kenya (APDK), a non government organization with close cooperation with the Government's Ministry of Medical Services, used both terms; rehabilitation and habilitation in the same sentence as disabilities (14).

In the authors' opinion, on several occasions, the physiotherapists introduced contradictive information. For example; the physiotherapists told the authors that treatment on a Bobath ball, in cases where seizures could be triggered, was a contraindication. Still children with this condition were treated using this method. Also massage was a contraindication for spastic musculature. Despite this previous statement several children with spasticity were treated with massage. The authors were told that children ought to be treated carefully to avoid fracturing their soft bone structure. Still the treatment seemed generally rough and it was especially concerning when the neck was treated, since it is such a sensitive area. What was the purpose of pushing the children so hard-handed during treatment?

Fortunately there were physiotherapists who were prepared to work within CBR, otherwise most children would not receive any treatment and would still be hidden. The physiotherapists observed, sometimes used techniques that seemed unnecessarily rough and the authors questioned whether the treatments were beneficial only or if there were also some unfavorable consequences' for the children. This question could not be answered by this study, but literature claims that rough and hasty movements may cause more damage than advantages, counteracting the contracture prevention (9). Concerning CP, it is just as important to exclude certain treatments, as it is to decide on which, why and how the physiotherapy treatment should be performed (4).

An increased cooperation and exchange, between Kenya and Sweden, may be of value for the global picture of physiotherapy. Internationally, this might increase the understanding of how physiotherapists contribute to the society and thereby improve the professional status. Further internationalization within physiotherapy might benefit a future with international guidelines and access to more treatment, based on evidence. Further research in this subject could also be of value and contribute to further development of physiotherapy treatment in Kenya.

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INFORMATION LETTER

2011-01-04

Information to participants

*"Community-Based Rehabilitation and Physiotherapy treatment of children with Cerebral palsy – Nairobi"*

You are enquired to participate in the project above.

We are two physiotherapist students from University of Lund. At the moment we are working with our Bachelor of Science in Physiotherapy. The title of our project is "Physical Therapy in Cerebral Palsy within Community-Based Rehabilitation Program, Nairobi, Kenya – a qualitative study". Our intention is to observe and get an insight into the techniques and tools the physiotherapists within CBR, in Nairobi, use in habilitation of children with cerebral palsy. We will write a report of our observations and compare it to habilitation of children with cerebral palsy in Sweden.

In our project we would like to observe and interview physiotherapists, who are working within CBR, and their patients during treatment. We are looking for physiotherapists and patients who are willing to participate in this project. Before every interview and observation we will ask all participants for their permission to record the session with video camera, digital camera and/or Dictaphone.

*Aim of study*

The aim of this study is to gain knowledge about the physiotherapist's role concerning habilitation of children with cerebral palsy within Community-Based Rehabilitation in Kenya. We opine that a project like ours, will contribute to increase the knowledge about how physiotherapists with decreased recourses, handle and solve problems.

Hopefully our project will be valuable for future research and emergency organizations. The material will be treated confidentially and the approval from each participant will be requested. Each participant has, throughout the whole project, the right to interrupt his/her participation and exclude the material that concerns them, without consequences. During treatments, we will not film or photograph any part of the body that can identify the physiotherapist, his/her patients (including relatives) or other participants. The participants will not be named or identified in any way.

Observe that the participation is optional, but we wish that as many as possible will attend. The material you provide us and the published results, will be de-identified and only be available to authorized persons. Confidentiality is secured.

This study pertain the Bachelor Degree Project at the Division of Physiotherapy at Lund University in Sweden.

For more information, please contact us or our supervisor by telephone or email.

Regards

*Anna-Maria Ringius and Louise Brandt*

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Institution for health, care and community  
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*"Community-Based Rehabilitation and Physiotherapy treatment of children with Cerebral palsy – Nairobi"*

Dear Dr Muli Kangutu

We would like to introduce ourselves, Anna-Maria Ringius and Louise Brandt, two physiotherapist students from the University of Lund, Sweden currently doing our fifth term. Susanne Brokop, head of office and also our supervisor, provided us with your email address and we are truly grateful for the opportunity you have given us to cooperate with the physiotherapist program at KMTC.

This term we are working with our Bachelor of Science in Physiotherapy. The title of our project is: "Physiotherapy in Cerebral Palsy within Community-Based Rehabilitation Program, Nairobi – a qualitative study". Our intention is to observe and get an insight into the techniques and tools the physiotherapists within CBR, in Nairobi, use in habilitation of cerebral palsy. If it is approved by you, patients and physiotherapists, we will use a video camera for documentation. The material will of course be treated confidentially and we will inform the participants that they are entitled to decline our request to observe and document their treatment. We will write a report of our observations and compare it to habilitation of cerebral palsy in Sweden.

We searched databases: PubMed, CINAHL and PEDro for information about Cerebral Palsy in Kenya and found no useful articles. Is it possible to find statistics on how many cases of cerebral palsy there is in Kenya? Could you recommend any trustworthy references?

When would it be possible for us to visit KMTC? We would prefer if it was possible to visit you during our summer holidays or the beginning of our sixth term. Also, we wonder about accommodation. Is it possible for us to rent a room at the Swedish school or what would be the most suitable option?

We are curious about how the cooperation with CBR is organized. Would it be possible for us to follow different physiotherapists during our visit? Susanne Brokop told us a little bit about transportation in and around Kenya but we would be grateful for further information.

Our plan is to finance this trip with money from a Minor Field Study scholarship or other scholarships, but we are going to Nairobi whether we get any sponsorship or not. This is something we really want to do. We believe it is important for us and our future profession to gain knowledge about physiotherapy in different parts of the world. When

teachers from KMTC visited our university last year we immediately decided that we wanted to visit your college.

The distribution of our project will be sent to you when we have translated it correctly into English.

Regards

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### **Questions to physiotherapists within CBR**

- For how long have you been working as a physiotherapist?
- Did you complete your education in Kenya?
- For how long have you been working within CBR?
- Are you working within CBR exclusively?
- What are your assignments?
- What is the difference between working in a hospital compared to working within CBR?
- How do you cooperate with other physiotherapists within CBR?
- Do you have any specific education or courses that qualify you to work with children with CP?
- How do you assess children with CP?
- Tell me about the intervention process.
- What do you think about the collaboration with the families?
- How do you perceive the knowledge of CP within the community?
- Tell me about children with CP and the school system?