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Challenges Faced By Cerebral Palsy Children at Kitwe Teaching Hospital, Zambia

Queen Mvula*

Department of Public Health, Copperbelt University, Michal Chilufya Sata School of Medicine, Ndola Campus, Zambia

Abstract

Cerebral Palsy (CP) is a neurological disorder caused by a non-progressive injury to the immature brain. It is one of the most common causes of physical disability in children with a prevalence of 2 to 2.5 per live births worldwide and 2 to 10 per 1000 live births in developing areas. The physical functionality of the affected children depends on the type and severity of the CP. There are different types of CP which includes spastic, dyskinesia, hypotonia and mixed type which affect developmental millstones differently. Children who are severely affected face more challenges than those who are moderately or mildly affected. The objectives of this study include; to identify challenges faced by cerebral palsy children, the mostly affected age group, the mostly affected gender, the most common delayed developmental milestone, the common types of cerebral palsy and the social economic status of CP children.

A descriptive cross section study was used and data was collected from 7th September 2020 to 26th October 2020 at Kitwe District at Kitwe Teaching Hospital, physiotherapy where participants were consecutively selected. In addition, an interview questionnaire was used to collect data on the challenges faced by the cerebral palsy children.

The study had 21 participants, out of which 14(66.7%) children were males and 11(52.4%) were in the age range of 4-6 years. The difference between the employed and unemployed in the ability to buy assistive devices was not significant. Only 3(14.3%) of the children were able to stand and walk out of which only 1 (4.8%) was able to run. In addition, 11(52.4%) had spastic cerebral palsy and 11(52.4%) of CP children had dental problems.

The study showed that currently, male CP children at Kitwe teaching Hospital in the department of therapy are the majority. Low social economic status of parents guardians had a negative impact on the rehabilitation of CP children. The most common type of CP was spastic and most delayed millstone was running. The majority of the children had dental problems.

There is need for more studies on CP in Zambia especially on the prevalence, and types of CP. In addition, more input of finances is needed for rehabilitation and social services such as education.

Keywords: Cerebral palsy • Dyskinesia • Neurological disabilities • Physiotherapy

Introduction

In the setting of multiple birth defects, the malformations of the brain are common which give rise to neurological disabilities. “One of the important causes of childhood neurological disabilities is brain injury occurring in the prenatal and perinatal period. These malformations include mental retardation, cerebral palsy, or neural tube defects, estimated at 1% to 2%”. However, among these malformations, cerebral palsy is the most common condition associated with spasticity in children and is defined as a disorder of movement and posture due to non-progressive injury to the developing brain and it is associated with disorders of speech, cognition and behavior and it can be accompanied by epilepsy. The injury can occur during neonatal or post neonatal period resulting into possible motor and sensory deficits that are mostly seen in early childhood.

The most common risk factors of cerebral palsy are low birth weight and perinatal hypoxia which accounts for about 50% and 10-20% respectively (surveillance of CP in Europe). Rare risk factors includes intrauterine or acquired infections such as rubella and

***Address to correspondence:** Dr Queen Mvula, Department of Public Health, Copperbelt University, Michal Chilufya Sata School of Medicine, Ndola Campus, Zambia, Tel: 974423271; E-mail: queenmvula36@gmail.com*

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toxoplasmosis, maternal placental illness, cerebral malformations, birth trauma, chorioamnoinitis, prothrombotic factors, acid base imbalance, indirect hyperbilirubinemia, metabolic disturbances and it can be sometimes genetically caused. Prematurity is an important risk factor for spastic diplegia while term low weight babies get quadriplegia or hemiplegia.

According to Sanger children with cerebral palsy have some hypertonic and hyperkinetic movement disorders. Hypertonicity can be caused by spasticity, dystonia and rigidity. Hyperkinetic means unwanted excess movements and the most common unwanted movements seen in cerebral palsy include athetosis dystonia, chorea, and tremors. Consequently, children suffering from cerebral palsy have limited ability to carry out their daily activities and also to participate in age appropriate activities.

Cerebral palsy is reported as occurring in approximately 2 to 2.5 per 1000 live births worldwide. In India, about 15% to 20% of the 3.8% disabled people are suffering from cerebral palsy. In addition, the prevalence of cerebral palsy in USA is approximately 3 to 4 per 1000 children [1].

According to a systemic review study that was established on what has been reported about cerebral palsy in Africa, it was found that the prevalence of CP in Egypt was 2 per 1000 birth, while in South African it was 10 per 1000 births. Nevertheless, since the prevalence and incidence of cerebral palsy in African countries such as Zambia it is difficult to assess and clarify, it is likely that there is a high prevalence of neurological impairments such as cerebral palsy in these areas. The purpose of this study was to determine challenges faced by cerebral palsy children at Kitwe teaching hospital.

Children with cerebral palsy experience a range of impairments that can negatively affect the whole body function and participation in daily life. As a result, these children face different challenges in Zambian communities. These challenges include, child neglect, social isolation, dental problems, hearing problems, sight problems, pain during physiotherapy, lack of hospital equipment's, lack of access to education and other morbidities such as epilepsy. However, most of the studies done in Zambia are more focused on the challenges faced by the caregivers to CP children. Therefore, this study was focused on challenges faced by CP children with the aim of providing information to both the community and health care services can be aware of challenges faced by these children in order to maximize their care and rehabilitation.

Materials and Methods

According to World Health Organization (WHO), global estimation of the population with disabilities is about 10%. In U.S, the prevalence CP is approximately 2.4 per 1000 children with males affected more than the females.

The study that was carried out in Australia in 2017 showed that the prevalence of cerebral palsy was 2.2 per 1000 neonatal survivors. In addition, the results obtained also showed that the most common predominant motor type was spasticity which was accounting for 80% and about 60% of children were independently ambulant. Other morbidities found were epilepsy, severe speech impairment, functional blindness and deafness

Another study was conducted in Pakistan on children aged between 4-10 years in the District of Swabi. Out of 1.3 million people of Swabi District, 278 had Cerebral palsy, out of which 68.7% were male and 45.5% were female. Hence the prevalence rate was recorded as 1.22/1000 live births. It was also found that most of the affected children where between the age of 9-10years and that 40.3% of children were severely affected. In addition, almost half of CP children (49.6%) had spastic quadriplegia.

According to the study that was done in Saudi Arabia, it was observed that Children with CP had a high risk of dental diseases. Those children with more severe neurological disability had higher risks of dental diseases. Some of the dental diseases observed were, dental erosion, bruxism, malocclusion and enamel defects which were as a result of motor and coordination difficulties, as well as limited oral care and hygiene.

The other challenge faced by CP children is social and emotion problem. Based on the study that was conducted in Jordan, it revealed that children with CP may have shyness, depression, feeling guilty when things are not going right, failure to express oneself, anxiety and getting upset in rage when they do not get what they wanted. In addition, some parents/guardians to CP children fail to take their children to the hospital due to fear of being stigmatized by the community [2].

A study done at the University Teaching Hospital of Zambia observed that most CP children had challenges in chewing food as a result some family member tend to lose patience and stop feeding the child especially when the mother is not around. Another challenge that was found is that parents/guardians face transport problem to take these children for physiotherapy every week due to lack of finances hence they stop taking these children for physiotherapy. In addition, it was also found that they are few physiotherapists leading to few sessions.

Another study done in Ndola District of Zambia found that most CP children are socially isolated from the community because people perceive the condition to be as a result of their parent's promiscuous ways and that a CP child is a curse. Some parents guardians have found that hospitals are unhelpful because most of them fail to buy assistive devices which are very expensive. It was also observed that the sponsorship of CP Africa has been given to those in the capital city while those from other towns have been ne neglected. To determine the challenges faced by cerebral palsy children for specific objectives:

- To determine the gender and age group mostly affected by cerebral palsy.
- To assess the social status of the cerebral palsy children.
- To determine the most common delayed milestone in cerebral palsy children.
- To identify the most common type of cerebral palsy.
- To identify CP associated comorbidities.

Although studies have been done on cerebral palsy in Zambia, most of them look at the challenges parents and guardians to CP children face. Therefore this study will help communities, health care services and NGOs become aware of the needs, love, care and attention these children require. In addition, the results obtained will call for the attention of the Non-Governmental organisations (NGOs),

research committee and the government to carry out more research on cerebral palsy.

Cerebral Palsy has negative impact on child development, child social activities and physical wellbeing of the child:

- What are the challenges faced by children with cerebral palsy?
- What are the most affected age group and Gender?
- What is the social and economic status for cerebral palsy children?
- What is the most common delayed developmental milestone?
- What are the most common types of cerebral palsy?
- What are the CP associated comorbidities?

This study was conducted at Kitwe Teaching Hospital, a third level health facility on the Copperbelt Province. It is located along Kuomboka Drive at plot NO.2831.The hospital was commissioned in 1958 and currently it has 664 bed capacity and with daily patient traffic of up to 1300. It undertakes the functions of teaching, research and development within the limits of available resources (Table 1) [3].

Variable type	Operational Definition	Indicator
Independent variable Age	Age of cp children	Age stated in years
Dependent variable social economic status	Income of parents/ guardians to assist in rehabilitation	Proportion of employed and unemployed
Dependent variable Type of cp	The most affected part of the body and the features of the affected part.	Either weak, stiff, shaking, or having unwanted movements. Whether unilateral, bilateral or The whole body.
Dependent variable Delayed milestone	If the child failed to attain milestones on time	Proportion of those who delayed in sitting, standing, Walking, running and talking
Dependent variable Other challenges	Associated comorbidities	Proportion of those who had dental problems, epilepsy, hearing problems, pain and Sight problems

Table 1: For independent and dependent variables for the study of challenges faced by CP children.

All children with cerebral palsy attending physiotherapy at Kitwe Teaching Hospital. The physiotherapy department was chosen for this study because it was easy to collect data as all the CP children were given a specific day. All CP children attaining physiotherapy at Kitwe teaching hospital from September 2020 to Novermber 2020.

- Sampling technique
- Consecutive sampling technique was used .
- Diagnostic Inclusion and Exclusion
- Inclusion criteria
- All children with CP whose parents/guardians gave consent too.
- Exclusion criteria
- Children without CP.
- CP children whose parents didn't give consent
- Children with other disabilities other than CP.
- Data collection techniques

Data was collected within two months, from September 2020 to November 2020. Information about the study was given to the participants and informed consent was obtained from participants. An interview based questionnaire was used as most of the parents/ guardians could not read or write.

Data analysis

The data was analyzed using a computer new software version SPSS (Statistical Package for social sciences).The ethical approval was obtained from the research and ethics committee, (TDRC) and before conducting the research, permission was obtained from senior medical superintendent, and the head of physiotherapy department at Kitwe Teaching Hospital. All the information gathered from this study was confidentially kept. Information about the study was given to the participants before seeking for consent from them to participate in the study. Participants were recruited based on their willingness to participate.

Initially, data was supposed to be collected from the department of physiotherapy and pediatrics clinic. However, the pediatrics clinic for CP children was closed due to the Covid-19 pandemic as a result data was only collected from the department of physiotherapy.

The findings might have been limited by the small sample size. Most of the parent/guardians didn't know how to read and write, hence, much time was taken to explain the questions to participants. Difficulties in getting accurate information about the developmental milestones as some children were brought by their guardians.

Results and Discussion

The table above describes the distribution of demographics in age and gender of the 21 participants. In terms of age, the majority [(52.4%)] were in the range of 4-6 years. In gander distribution, the majority [(66.7%)] were males.

The table above is explaining the relationship between employment and the ability to buy assistive devices. Out of the 19 parents guardians who were asked to buy assistive devices, only 4(33,3%) of the employed and 2(28.6%) of unemployed were able to buy.

According to the table above, the majority (95.2%) of the children did not attain the milestone of running.

As indicated in the table above, the most common associated comorbidities was dental problems with 11(52.4%) (Table 2) [4].

	Variables	Frequency	Percent (%)
Age of the child	< 3years	4	19
	4-6years	11	52.4
	07-Sep years	6	28.6
Gender	Male	14	66.7
	Female	7	33.3

Table 2: Demographics for CP children.

This study was done to determine the challenges faced by cerebral palsy children among children attending physiotherapy at Kitwe teaching hospital. In this study 21 parents/guardians who came with CP children for physiotherapy were consecutively picked and interviewed. According to the findings, the male gender was the majority. This was a similar finding with the critical review that was done on the 32 studies in Sweden. In addition, most of these children were between 4-6 years of age. Those between 7-9 were very few and were not attending physiotherapy frequently. This is as a result of parents/guardians who had children between the age of 7-9 years had become more experienced and could do physiotherapy at home. Meanwhile others it is because they could not see any improvement and stopped bringing their children for physiotherapy.

In this study, it was observed that social and economic status of parents/guardians had negative impacts on the rehabilitation of CP children. These negative impacts include: failure to buy assistive devices and lack of transportation to bring the children for physiotherapy. Out of the 12 employed (both formal and informal) parents/guardians, only 4 were able to buy assistive devices while 2 out of 5 of unemployed were able to buy assistive devices. Therefore, the difference between the employed and unemployed parent's guardian's ability to buy assistive devices was not significant. This might be as a result of the study having a small sample size. The other reason is some parents who were formerly and informally employed were earning little money to afford buying assistive devices. Lack of transportation to bring these children for physiotherapy resulted into children missing some physiotherapy sessions. Consequently, there was minimal improvement in those who were missing some sessions and those who had no assistive devices. A study that was done in USA also showed that low socioeconomic status results in limited healthcare access due to lack of transportation and insurance leading to poor health outcome in CP children.

That spastic CP was the most common type followed by dyskinesia, hypotonic and then mixed type. However, the most common spastic CP subtype was found to be spastic hemiplegia followed by spastic diplegia and only few had quadriplegia. This was a similar finding with a study which showed that spastic CP was the most prevalent. However, on the subtypes of cerebral palsy, some studies have shown that spastic diplegia is the most common type of CP.Most children with spastic hemiplegia and diplegia have good prognosis with high functional abilities. Meanwhile those with spastic quadriplegia have poor prognosis with significant functional limitations, cognitive impairment, epilepsy, hearing impairment and sight problems.

In this study it was observed that most of the children had delayed millstones. Out of the 21 children, 15(71.4%) delayed to sit, 16(76,2%) delayed to craw, 18(85.7%) delayed to stand and walk. However, out of the 21 CP children only 1(95.2%) was able to run. Therefore, this means that a higher percentage of CP children have delayed developmental milestones with running being the most affected (Table 3).

	variables	n/%	Milestones
sitting	</= 7 months	6(28.6%)	attained on time
	> 7 months	15(71.4%)	delayed
crawling	</=9 months	5(23.8.%)	attained on time
	>9 months	16(76.2%)	delayed
standing	</=11 months	3(14.3%)	attained on time
	>11 months	18(85.7%)	Delayed
walking	</=12 months	3(14.3%)	attained on time
	>12 months	18(85.7%)	delayed
Able to run	</=18 months	1(4.8%)	attained on time
	>18 months	20(95.2%)	delayed
Say one word with meaning	</=10 months	6(28.6%)	attained on time
	>10 months	15(71.4%)	delayed
construct a sentence with meaning	</=15 months	2(9.6%)	attained on time
	>15 months	19(90.5%)	delayed

Table 3: Developmental milestone.

Some parents/guardians explained that delayed milestones had affected their children socially as they were unable to go to school because most of them required wheel chairs, and having someone to take them to school every day. In addition, they also explained that these children fail to play like other children in the community due to their inability to walk and some due to inability to talk. According to the study that was conducted in USA, is was found that CP children with spastic diplegia, and hemiplegia eventually attained the entire milestone while those that had spastic quadriplegia could not. However, according to the finding in this study, those with spastic diplegia and hemiplegia failed to attain all the milestones even at the age of 7. This might be due to failure of parents/guardians to take their children for physiotherapy more frequently.

According to the findings in this study, some CP children had associated comorbidities such as epilepsy, sight problems, dental problems and hearing problems, with dental problems being the most common associated comorbidities. A certain study observed that dental problems were as a result of severe factors which includes motor difficulties, lack of muscle coordination, limited oral care and hygiene.

That 30% of CP children in this study had epilepsy. This was a similar finding with a study conducted by Boulenouar and others which found that epilepsy occurred in about 30% of CP children with early symptoms starting within two years of life.

Another study revealed that Visual abnormalities such as refractive errors, strabismus, nystagmus, amblyopia and cortical visual impairment were common in cerebral palsy, among them refractive errors and strabismus were the most common. According to the findings in this study, it was found that 28.6% of CP children had sight problems and most of them had strabismus (Table 4) [5].

In this study, 38.1% of the parents/guardians explained that children experience a lot of pain during physiotherapy. They further explained how these children cry frequently at home due to muscle stiffness. Most of these complaints came from parents/guardians with spastic CP children.

Variable	Frequency	Percent

Dental problems Yes		11	52.4
	No	9	47.7
Hearing problems	Yes	3	14.3
	No	18	85.7
Sight Problems	Yes	6	28.6
	No	15	71.4
Pain during physiotherapy	Yes	8	38.1
	No	13	61.9
Epilepsy	yes	6	30
	No	15	75

Table 4: CP associated comorbidities.

However, another study has shown a higher percentage (75%) of cerebral palsy children experiencing pain.

Hearing problems was another challenge these children experienced. According to table 1.5 above, 14.3% of CP children had hearing problems with varying degree of severity. Hearing problems interfere with speech and language development.

Conclusion

This study showed that at Kitwe Teaching Hospital in the department of physiotherapy, the majority of CP children are males with the age range of 4-6 years being the most predominant. The social and economic status of parents guardians play an important role in the rehabilitation of CP children. The types of CP and delayed developmental milestones limited CP children to participate in social activities such as going to school and playing with other children. CP was also associated with pain and other comorbidities such as epilepsy, dental problems, hearing impairment and sight problems.

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Recommendations

More research is needed to determine the incidence rate of cerebral palsy in Zambia. There is need to robust policies, financial and human resource investment on the care for CP children.

More studies are also need to determine the most common type of cerebral palsy and the most common CP associated comorbidities in order to make interventions on the needs and care for CP children. There is need for the health care finances to be allocated to buying wheelchairs and transportation for CP children.

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