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## Assessment of mothers' knowledge and practices towards their children with cerebral palsy in a rehabilitation center

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### Abstract

**Background:** The Cerebral Palsy Center works closely with rehabilitation, including occupational, physical and speech therapists under a good regulation.

**Aim:** To evaluate knowledge and practice on mothers who have children suffering from cerebral palsy which attend to rehabilitation centers

**Methods:** This rehabilitation centers-based cross-sectional study was conducted in order to assess the knowledge and practices of the 70 Mothers attending to Cheshire home and Osratna rehabilitation center, Sudan center and Sakena center with their children diagnosis cerebral palsy during the study period. Cerebral palsy was defined as mothers knowledge and practice, beside mothers group discussion and interview for employees.

**Result:** Result: 42.33% of mothers had no idea about the disease causing their children's disability, and 51.9% of them applied practical treatment procedures accurately to their children with disabilities.

**Conclusion:** Most mothers have poor knowledge of the nature of cerebral palsy, which can lead to serious consequences. Overall, most mothers reported unsatisfactory work practices. There is a statistically significant relationship between mothers' sociodemographic data, their knowledge, and reported practices.

**Recommendations:** Provide an education program for mothers about prenatal care and, how to care for children with cerebral palsy design booklets and leaflet.

**Keywords:** Mothers' Knowledge, Mothers' Practices, Children, Cerebral Palsy, Rehabilitation Center.

## Introduction

Cerebral palsy (CP) is a neurological developmental bug – disorder discriminated by distortions of muscle elasticity, movement and motor dexterities, and is attributable to brain developmental injury <sup>(1)</sup> Asymmetric segmental in motion were stoutly linked with unilateral CP <sup>(2)</sup>. This clinical feature took a long time, and cerebral palsy was not discovered until after 3-5 years of age (3). The number of newborns with cerebral palsy is approximately 2 to 3 children out of 1000 healthy children, and this silent disease causes many of them to suffer a minor stroke and lose their balance (4). The completely new movement results in radical paralysis leading to spasticity, or what is called ataxia. Then the spasticity changes and becomes permanent, the clinical features of this entity evolve over time and the specific CP syndrome may be recognizable only after 3–5 years of age <sup>(3)</sup>. Cerebral palsy, which occurs in two to three out of 1,000 live births, has multiple etiologies resulting in brain injury that affects movement, posture, and balance. <sup>(4)</sup> The movement disorders associated with cerebral palsy are categorized as spasticity, dyskinesia, ataxia, or mixed/other. Spasticity is the most common locomotors bug-a disorder, occur in 80% of children with cerebral palsy. Movement maim from cerebral palsy can lead to secondary trouble, including problem in hip lead to pain or dislodge, problems in balance, equinus deformity, and hand dysfunction. <sup>(5)</sup> CP is discriminated by dissimilarity in

risk imperils, waked particular etiology, clinical features, The severity of the normal functional limitations, the secondary conditions surrounding them, the multiple treatment options, and the progression of the condition over the individual's lifespan. (6) Shevell in nineteen's Suntory views cerebral palsy as a spectrum disorder of the body and not a clinical disease (7). The prevalence rate of CP for all live births ranges from 1.5 to 3 per 1,000 live births, with variation between developing and least developed countries and geographical area. (8) In this Review, there an average decline in the live birth prevalence of Cerebral Palsy in some developed nations, describe the epidemiological evidence for risk factors, (9) such as preterm birth and fetal growth retardation, genetics factors, infection during pregnancy and other exposures, and discuss the success achieved so far in prevention through used of magnesium sulfate for preterm labor and treatment for baby with low temperature and low oxygen. (10) In many infants and children, Neurological and motor. (10) In many infants and children, Neurological and motor abnormalities tend to improve over the first few years, especially during the first five years of life, although the reported prevalence of cerebral palsy tends to increase during infancy. There for premature baby and low birth weight are main cause of CP, there are multiple other factors which associated with increase the risk for CP. several epidemiological studies have reported that up half of all children who suffering from Cerebral Palsy were born at full term without any risk factor for their functional status. (11)

The patho-physiology associated with movement disorders remains somewhat unknown. Emerging hypotheses include an imbalance between onset and non-onset in the nodal group, sensory processing disorder, and disabled plasticity in the basal ganglia. (12)

## Research Problems

Cerebral palsy is widespread in Sudan due to limited access to prenatal and neonatal care, limited health and research resources, the impact of health and economic

conditions, and a general lack of awareness of cerebral palsy and the importance of research into it.

## Objective

- **General:** Assessment Knowledge and practice on mother'with their children with cerebral palsy.
- **Specific:**
  - Assessment mothers' knowledge of cerebral palsy, toward causes, symptoms, and treatment methods
  - Assessment level of practical carried out by mothers towards their children with cerebral palsy

## Methodology

A cross-sectional study was conducted in rehabilitation centers. We collected available data from mothers who attended Cheshire Home, the Sudan Center for Down Syndrome and Other Disabilities, Our Family Rehabilitation Center, and Sakina Center with their children with disabilities. A total of 70 mothers were included. Tools of the study: Structured observational check list and interview questionnaire was consisted of five tools for data collection. First tool included socio-demographic data, characteristics of mothers and their children. Second tool: Mothers' history about CP. Third tool: type of child disabilities scale. Fourth tool: Mother' knowledge and fifth scale observational check list for mothers practices Also held focus groups discussion with mothers and interviewed administrators at rehabilitation centers. We conducted a systematic analysis used SPSS version 16.

## Result

Table (1): Demographic data

	%	%	%	%
Disable child age	5< (53)	5 – 10 (14)	> 10 – 1 (33 )	
Family income	Poor (47)	Moderate (52)	High (1)	
Monthly income	Enough (36)	Not enough (64)		
Mother Education	Illiteracy (19)	Primary(21)	secondary (33)	University (27)
Is the mother work	Yes (22)	No (78)		
Is the work harm the mother	<b>none</b>			
Is there is another disable person in family	Yes (15)	No (85)		
The relation between them	Sister (5)	brother (4)	ant\ankel (6)	

In my study 53% of disable children aging below 5 years, 47% their family poor income. 19% of mother illiteracy while 27 graduate from university, 78% of mother house wife and 22% them their working is safety. About 15% of all cases having another disability in their family, 5% ranked from sister while 4% brother and 6% second relationship.

Table (2): Mother history

	%	%	%
Age at marriage	>35 (10)	<35 (90)	6 – 9 (21)
Number of delivery	1 – 5 (79)	6 – 9 (21)	
Disable child ranker	1 <sup>st</sup> (43)	Middle (19)	Last (38)
All your babies have breast feeding	Yes (95)	No(5)	
Breast feeding duration ( month)	6> (6)	>6–12 (23)	>13–24 (69)
Mother age during pregnancy	14 - 25 (21)	26 -35 (35)	36–42 (44)
Relation between mother and her husband	1 <sup>st</sup> (28)	2 <sup>nd</sup> (28)	3 <sup>rd</sup> (44)
Is the husband smoker	yes (22)	N0 (88)	
I Is the husband Alcoholism	yes (9)	N0 (91)	
Is mother Suffering from infection during pregnancy	yes (16)	N0 (64)	
Is the mother take hormone when pregnant	yes (17)	N0 (91)	
mother exposure to radiation during pregnancy	yes (7)	N0 (93)	
Is mother take contraceptive pills when pregnant	yes (9)	N0 (91)	
Is mother Suffering from fever during pregnancy	yes (23)	N0 (77)	
Is mother Suffering from bleeding during pregnancy	yes (9)	No (91)	
Is mother Suffering from low O2 during pregnancy	Yes (36)	No (64)	
Taken thyroxin hormone	yes (9)	No (83)	

90% of mothers married under the age of 35 years old, 79% were delivered 1 -5 children, while 21% were delivered from 6-9 kids. 43% first baby was disable. 95% taken breast feeding. 44% no relation between couples. 22% of husbands smokers and 9% alcoholism, during pregnancy there is 16% suffering from infection, 23% suffering from fever, 9% suffering from bleeding and taken contraceptive pills between babies, 36% exposures to low O2 level during delivery. when there is 7% exposure to the radiation. Also, there is 9% taken hormones and 17% taken thyroxin hormone.

Table (3): Percentage of disable child

	Yes %	No %
Difficult in movement	84.3	15.7
Nutritional problem	41	59
Difficult to swallowing	42.9	71.40
Teething and gum problems	22.9	77.1
<b>Sensory problems</b>	<b>20</b>	<b>80</b>
Visual problems	7.1	92.9
Speech problem	38	62
Suffering from chest infection	24.3	75.7
hearing problems	1.4	98.6
Suffering from otitis media	2.8	97.2
Drooling problem	22.9	77.1
Behavioral problem	27.1	72.9
Lack of elimination control	35.9	64.1
Suffering from epilepsy	6	94
Learn disability	57.1	42.9
Intellectual disability	58.6	41.4
Suffering from constipation	25.7	72.9
Lack of growth	44.3	55.7
Suffering from epilepsy	8.6	91.4
Suffering from deformities	81.4	15.7

84.3% from disable child in study have difficult to move, 43 % of children have nutritional problem. 1.4% hearing problems,20% sensory problems,7.1% have visual problem, 38% have speech problem, 23% suffering from drooling and inflammation of the gums and teeth, 6% developed epilepsy, 35.9% lacking in elimination, 57% learning disability and 58 intellectual disability, 44% growth lack.

Table (4): Mother knowledge for cerebral palsy

	Yes%	No%
Is cerebral palsy permanent disability	55	45
Is fever caused of cerebral palsy	45	55
Is bleeding caused of cerebral palsy	23	77
Is medication caused of cerebral palsy	38	62
Is radiation caused of cerebral palsy	34	66
Is chemical caused of cerebral palsy	44	56
Is low O2 caused of cerebral palsy	67	33
Is hereditary caused of cerebral palsy	55	45
Is exlampsia caused of cerebral palsy	20	80

42.33 % of mothers not knowledgeable about diseases which caused disable for their children.

Table (5): Mother practice

	Yes %	No %
Mother were done exercise for their children	74	24
Exercise to strength muscle for neck and shoulder	70	24
Their children have movement devices	44	50
Preparing special diet for their child	37	4
Preparing soft meals for their children	36	8
trained their child for an audio, senses and tactile sensations of internal joints and muscles to compensate for loss of vision	100	0.00
Workout on lips and tongue	28	72
Used special and soft brush for their child	24	4
Used saline solution to clean their child teeth	20	8
Take position to decrease convulsion	100	0.00

About 74% mother care full their child exercise and 70% to strengthen neck and shoulder muscle, and 44% moving wit device. 90.24% of those children their mother preparing special diets and 87.8% prepared soft meals for them. 100% of those children their mother workout to train their child an audio, senses and tactile sensations of internal joints and muscles to compensate for loss of vision. 28% of those children their mothers workouts own lips, tongue and jaw muscles to teach them, 24% from children having teeth problem used smooth brush and 20% used

saline solution to clean their child teeth, all mothers take special position when their child developed convulsion.

### Group Discussion:

**Cheshire:** Cheshire group said the number of disable children increase monthly this supported by "negative and positive" factors. The positive side was linked to the awareness of people going to seek treatment and rehabilitation center, beside families are comparing the normal child with the disabled, and there are another negative side, the lack of awareness programs to protect child from disability and fixed rehabilitation centers in capital. And also said there are therapeutic programs for mothers and families they participate in it, and contribute to the mother effectively, where the child does not come daily for treatment and the mother is trained to do exercises for her child at home (mother practice). After three months, the child is knew and evaluated.

The challenge Practitioners in the field of physiotherapy in Sudan are few, and their wages are very high. Also they talking about substance import for disabled aids like wheel imported from China are not made for our environment, land and our disabled people, after a month or two break down, and if had materials in the local market why imported from abroad, and the materials in the law are aids such as chairs, blind sticks and we need Only for accessories to complete the work and if we brought it to be held accountable by customs, there is no flexibility of the dealers in that the accessories are complementary to the appointed. There are also workshops for the manufacture of splinting, artificial limbs, and chairs made by the disabled, also there is the Cheshire band song. The group said all the services are available.

### Interviews:

**Usrtuna Center:** Is a non-governmental, not for profit society working to provide equal opportunities to disabled children and ease their active integration in the

society, through services like physical rehabilitation, community based rehabilitation, education and vocational training, and with the participation of disabled children in their families, society, institutions with competence and qualified staff, official bodies and associations of similar jurisdiction. It has receives all cases except autism and sclerosis there are ten labs, maintenance and transportation services. The capacity of center is about 300 cases. The center supported by external Aid. The massage for center is handicapped rehabilitation capable to production and organizations.

**Sakena Center:** Group from Sakena center talking about neglect from government and some services not available like nutritional and physiotherapy services they transfer cases to Chiesher and Ustratuna to seeking physiotherapy and also there is pharmacy without pharmacist.

#### **Sudan Center for Down Syndrome and Other Disabilities:**

They train staff on international programs and technologies to work in this field. This rehabilitation center which support families of low-income Down syndrome children and other children with disabilities to train and care their children at homes. Also the center works to raising awareness among the community about the importance of caring for those children and their potential contribution to the development in society.

#### **Discussion**

According to demographic data 53% of disable children aging below 5 years, 47% their family poorly income. half of mothers had primary and secondary institute education, <sup>(13)</sup> three quadrant of mother house wife and 22% them their working is safety. About 15% of all cases have another disability in their family, ranked from sister, brother and second relationship. <sup>(14)</sup> There are increase number of disability may be related to increase number of birth, about 42.86 women birth between 6 – 9

babies. Also increased proportion of first child suffering from cerebral palsy may be related to poor antenatal follow up, because there is variation mothers participants some of them said they had been subjected to a lack of oxygen during birth and some said they have suffered from bleeding when pregnancy, fever, infection and little stated that they are taken hormone during pregnancy and very little stated they had been exposure to radiation in both this in line with other study said Prematurity and low birth weight are important risk factors for CP; however, multiple other factors have been associated with an increased risk for CP, including maternal infections, and. In most cases of CP the initial injury to the brain occurs during early fetal brain development; and hemorrhage are the main pathologic findings found in preterm infants who develop CP <sup>(4, 9, 15)</sup> when there is 7% exposure to the radiation during pregnancy. Also 84.3% from disable child in study have difficult to move, <sup>(12)</sup> minimum children having hearing problems and otitis media while 38% having speech problems <sup>(5,16)</sup>, 20% sensory problems, 7.1% have visual problem, 43 % of children have nutritional problem fifth suffering from drooling and inflammation of the gums and teeth this related to poor mother practice. <sup>(17)</sup> More than half having learning and intellectual disability <sup>(18)</sup>. In our study found a large number of mothers do not have sufficient knowledge about the nature of the disease, despite the large number of children suffering from cerebral palsy. But about 55% of mothers know that cerebral palsy is a permanent disease, and many mothers prevent their children from marrying into families with disabled children for fear of transmitting the disease to their grandchildren.

However, we find a large number of mothers performing practical work for their children with disabilities with high skill, this retain to Sudanese disability children live with the family at home and depends on their mothers in dealing at the same time. This applicable with study done in Egypt. <sup>(19)</sup> Second study said family caregivers of child with cerebral palsy has many knowledgeable gaps regarding illness of their children. Third study reported that mother were decreasing knowledge

for how to deal their children and how to make of using coping strategies for dealing their child. Also, they do not have enough knowledge for caring in relationship to between family and child. <sup>(20)</sup> Most mothers had appeared great openness toward acquiring new skills for dealing their children with cerebral palsy. Although, mothers have appeared more practice in handling their children problems. This matching with other study said most families had shown great openness toward acquiring new skills and knowledge for handling their children with intellectual disability. However, tribal parents have shown a more humanitarian approach in handling behavior problems in children. <sup>(21, 22)</sup> while there is a more entire mother they trained their children for audio, senses and tactile sensations of internal joints and muscles to compensate the loss of vision. Supported by study said the training, very frequently offer advanced forms of visual rehabilitation such as intensive training in device use, orientation and mobility training. <sup>(23, 24)</sup>

## Conclusions

Overall, mothers demonstrated good scores practice toward the care of children with CP. with a special emphasis on improving their children with movement, the rehabilitation center need to support from government. A considerable lack of knowledge in handling their children signifies a gap in care, which could have potentially life-threatening consequences. Additionally, our findings highlight the importance of enhancing communication between healthcare providers, and family it also emphasizes the need for promptly referring children with CP to relevant experts for the earliest possible intervention.

## Recommendation

- Rehabilitation centers should be supported by a number of professionals in various fields. (Physiotherapist, nurses, and occupational therapist and speech therapy ... etc).

- Establishing multidisciplinary rehabilitation centers and distributes them to cover all the country by ministry of health and social affairs.
- Raising awareness among mothers about prenatal care and, of course, how to care for children with major paralysis.

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## Appendix

CP: cerebral palsy.