RESEARCH ARTICLE

ESTABLISH REGISTRY OF CEREBRAL PALSY IN MINIA GOVERNORATE

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ARTICLE INFO

ABSTRACT

Background: The current study was conducted to establish registry for physical therapy database of cerebral palsy patients in Mina city and its surrounding cities including (Maghagha, Matty, Mallawi, Samallott, Abu-Qurqase and Deirmawas). Children with CP were recruited from hospitals of health ministry (general hospitals), insurance hospitals, pt centers, private hospitals and units of family medicine in Minia governorate. Children were of both genders and their age ranged from birth to 18 years old.

Materials: The outcome measures were Gross Motor Function Classification System (GMFCS), Gross motor function measure (GMFM) from birth to 18 years, Manual Ability Classification System (MACS) and Viking Speech Scale.

Results: The results revealed that the children with CP who received physical therapy services were 221 and children who did not receive physical therapy services were32, children49% were from relative parents, 63.2% were living in rural and 76.3% Presented by obstruction. classification of CP based on GMFCS were 4.7% for level I, 31.6% for level ll, 37.2% for level lll, 25.7% for level IV and 8% for level V. Viking Speech scale declared 32.8% for level I, 33.6% for level II, 19.8 % for level III and 13.8 % for level IV. Our results revealed that there were significant relation between GMFM, MACS, GMFCS, VIKING scales and CP.

Conclusion: The current study revealed that prevalence of CP in Minia governorate was 253 children representing 0.088 per 1000 live births. The spastic type 57.3% was the most common while dystonic type was the least 7.9%. Demography revealed that 60.5% of children were males and 38.5% were females, 36.8% of the cases were from urban and 63.2% were rural High incidences of children with CP were level III using GMFCS, MACS and level II using Viking speech scale.

INTRODUCTION

Patient registries are collection of secondary data related to patients with specific diagnosis, condition or procedure. Registries are different from indexes in that they contain more extensive data. They can be a powerful tool to observe the course of disease; to understand variations in treatment and outcomes; to examine factors that influence prognosis and quality of life; to describe care patterns, including appropriateness of care and disparities in the delivery of care; to assess effectiveness; to monitor safety and harm; and to measure quality of care. Through functionalities such as feedback of data, registries are also being used to study quality improvement (LaBresh, *et al.,* 2003; McNeil *et al.,* 2010). Cerebral palsy is the most commonly occurring childhood physical disability (Shevell and Bbodensteiner, 2004), with an overwhelming majority of its global burden in low-resource countries. It has been estimated that 80% of the global prevalence of CP is in low-resource countries, having larger populations and potential greater incidence rates. Children who have a disability and their families living in low resource countries are among the most disadvantaged in their

community, with a bidirectional link between disability and poverty (World report on disability, 2011). The purpose may be monitoring trends, planning services or evaluating care, either leading or not leading to specific studies. However, the stated purpose might change over time; thus, it is also important to keep in mind that with changing needs and technologies, the data that need to be collected may also change (e.g., magnetic resonance imaging results for children with CP) (Cans *et al.,* 2004). Cerebral palsy registry has explained significant knowledge regarding the prevalence, cause, distribution, frequency, and severity of cerebral palsy throughout the world. In order to monitor prevalence rates, especially within subgroups (birth weight, clinical type), it is necessary to study large populations**.** Such registry could help in infrastructure of services provided in the physical therapy unit according to level of impairment of CP children in assisting with successful interventions pertaining to the prevention of CP and improve function and quality of life for those who have this disorder (Shevell, 2004). The current registry provides a coordinated data base collection system for CP in minia governorate which hadn't been conducted before. It's a part of a national project to register CP all over Egypt. It's believed that this project will improve research quality by providing large population sample and describing our need for social and health services for children with CP.

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MATERIALS AND METHODS

253cases of cerebral palsy in Minia governorate there age ranged from birth to 18 years old were included in this study and assessed by GMFCS, GMFM, MACS, and Viking Speech Scale

*Cerebral palsied children from both sexes.
*Children were collected from:

- General hospital in Minia governorate.
- Health Insurance Hospital in Minia governorate.
- Units of family medicine city.
- PT centers

Assessment by

1-GMFCS
Gross Motor Function classification system: It is a classification system developed for children with CP.It is a practical system that can be used in clinics by the rehabilitation team to classify a child with CP, observe the efficiency of the applications and follow –up of the patients (Palisano *et al.,* 1997).

2-GMFM

Gross Motor Function Measurement: The purpose is to determine the capacity and change of case prognosis. It is a standardized observational instrument designed and validated to measure change in gross motor function over time in children with CP. (Russell et al. ,2013).

3-MACS

Manual Ability Classification System: Is a system developed in 2003 by Elioson. In order to classify the ability to hold objects with hands during daily activities of children with CP between the ages of 4-18y.children below 4 years were assessed by observation and interview with parents. Manual Ability Classification System aims to specify which level represents best the child's normal activities at school, home and in society **(Eliasson *et al.,* 2006).**

4-Viking speech scale

This scale has been developed to classify children's speech production. The Viking Speech Scale was developed for use with children aged 4 years and above. Children below 4 years were assessed by observation and history from the parents **(Lindsay *et al.,* (2010).**

Procedure

This study was conducted from November 2017 up to March 2018. The Approval of the ethical committee of the faculty of physical therapy was obtained before the start of the study. In addition all parents of included children consented on their participation in the study. The application time for each child ranged from 15minutes up to 45 minutes. The time of the day where the child would be at optimal condition for performance was determined for each child individually with the help of the parents or caregiver. The caregiver did not help the child during evaluation.

The researcher observed the children and recorded the level of their activity according to their age. Good environment to encourage the child to do his best effort was employed, the room was large enough to be comfortable for the application; Suitable clothes for the child were used, Smooth firm surface, Stop watch and Interesting toys were been used.

Statistical Analysis

Data were analyzed using SPSS version 20. Data were presented as mean ± SD for normally distributed. For qualitative data, chi- square (x^2) was used for comparisons between groups. For all tests P < 0.05 was considered to be statistically significant and P <0.01 the correlation was considered highly significant.

The mean and standard deviation for GMFM score were (158.14) with st.d=59.16 and 95% confidence interval. GMFM scores ranged from 144.42 to 161.86.

Cerebral Palsy Subtypes:

Table 1. By Cerebral Palsy Subtypes

Variable	Freq.	%	Rank
Quadriplegia	36	14.2	2
Diplegia	50	19.8	1
Triplegia	5	2.0	10
right hemiplegia	14	5.5	9
left hemiplegia	21	8.3	6
Monoplegia	19	7.5	8
Mainly athetosis	27	10.7	4
Mainly dystonia	20	7.9	7
Ataxia	34	13.4	3
Hypotonia	27	10.7	4
Total	253	100	-

GMFCS Level:

Table 2. By GMFCS Level

Variable	Freq.	%	Rank
Level I	12	4.7	4
Level II	80	31.6	2
Level III	94	37.2	1
Level IV	65	25.7	3
Level V	2	0.8	5
Total	253	100	-

MACS Level:

Table 3. By MACS Level

Variable	Freq.	%	Rank
Level I	27	10.7	4
Level II	79	31.2	2
Level III	85	33.6	1
Level IV	61	24.1	3
Level V	1	0.4	5
Total	253	100	-

Viking scale Level:

Table 4. By Viking scale Level

Variable	Freq.	%	Rank
Level I	83	32.8	2
Level II	85	33.6	1
Level III	50	19.8	3
Level IV	35	13.8	4
Total	253	100	-

Total GMFM Score:

Table 6. By Total GMFM Score

Variable	Freq.	%	Rank
Less 115	62	24.5	3
From 115-160	67	26.5	2
From 161-200	56	22.1	4
More than 200	68	26.9	1
Total	253	100	-
Mean	= 158.14		
Std. Deviation = 59.16			

Relationship

To study the relationships between CP performance and selected sample parameters. chi-square test was used to test for the relationship and contingency coefficient was used to test for the strength of such relationship.

Table 7.

Onset Of CP Variables	Chi- square	Contingency Coefficient	P- Value	Sig.	Indication
3-Smoking state	4.25	0.129	0.119	Not Sig.	There is no Significant relation
9-Complication during pregnancy	14.11	0.230	0.001**	Sig.	There is Significant relation
10-Medications during pregnancy	14.71	0.234	0.001**	Sig.	There is Significant relation
11-Gestational Age	8.41	0.179	0.078	Not Sig.	There is no Significant relation
15-Child Age	14.73	0.235	0.065	Not Sig.	There is no Significant relation
16-Child sex	0.690	0.052	0.708	Not Sig.	There is no Significant relation
17-Child weight	16.44	0.247	0.037*	Sig.	There is Significant relation
18-Child birth order	26.27	0.307	0.001**	Sig.	There is Significant relation
19-1-Epilepsy	4.82	0.137	0.090	Not Sig.	There is no Significant relation
19-2-Intellectual	2.76	0.104	0.252	Not Sig.	There is no Significant relation
19-3-Visual (by following object)	2.57	0.100	0.276	Not Sig.	There is no Significant relation
19-4-Hearing (by following sounds)	0.899	0.060	0.638	Not Sig.	There is no Significant relation
19-5-Speech	3.55	0.118	0.169	Not Sig.	There is no Significant relation
19-6-Swallowing(according to age)	2.730	0.103	0.255	Not Sig.	There is no Significant relation
21- Were any birth defects present	34.17	0.345	0.001**	Sig.	There is Significant relation
21a-Is there a known syndrome	24.05	0.295	0.001**	Sig.	There is Significant relation
23-Giving delivery by	28.64	0.319	0.001**	Sig.	There is Significant relation
24-Location of delivery	13.41	0.224	0.001**	Sig.	There is Significant relation
25-Delivery intervention	10.05	0.196	0.007**	Sig.	There is Significant relation
26-Weight at delivery	19.29	0.266	0.004**	Sig.	There is Significant relation
27-Receive physical therapy	17.30	0.253	0.001**	Sig.	There is Significant relation
28-Cerebral Palsy Subtypes	25.02	0.300	0.124	Not Sig.	There is no Significant relation
29-GMFCS level	21.69	0.281	0.006**	Sig.	There is Significant relation
30-MACS level	21.61	0.281	0.006**	Sig.	There is Significant relation
31-Viking scale level	17.63	0.255	0.007**	Sig.	There is Significant relation
32-Total GMFM score	5.02	0.139	0.541	Not Sig.	There is no Significant relation

** Significant at level less than (0.01)

* Significant at level less than (0.05)

DISCUSSION

This study was performed to register children with CP in general hospital, health insurance hospitals and most private physical therapy centers in minia and its neighboring cities which are (samlott, matty, maghagha, mallawy, abo-qurqas and dairma was. We came to accept the hypothesis of the current study "which was no CP registry in Miniagovnorate". All CP children from birth to age 18 and diagnosed as CP were included in this study. The following data was taken from unit of anticipation and monitoring in ministry of health and population in Minia governorate. Latest information about population in the target area established in 1/1/2018 were (5497095), with (1742923) urban in the target area representing (31.7 %) and (3754172) rural (68.3%). Male were (153) with percent (50.6%) and female were (100) with percent (49.3%). Children under 18 years were 2868107(52.17 % of total population) target populations for this study.

Prevalence of cp

The current study revealed that the total CP cases who referred to receive physical therapy services in Minia Governorate were

221case representing 0.088 per 1000 live birth from the targeted population, although physiotherapy often constitutes a major part of the team approach in rehabilitation of CP. However there was great defect of physical therapy services to these patients due to low cultural level of the caregivers. The lower incidence in Egypt generally and in this study in particular may be due to lower education of level cultural believes, lack of physical therapy services and social factors as the parents tend not to give information about their CP children and the economical status to receive proper therapy in hospitals or centers. The current study revealed positive consanguinity about (49%) which contradict with Fidan and Baysal, (2014) who reported that the percent was 24.6%.and agree with El- Tallawy *et al.,* (2011) who recorded that the most commonly recorded risk factors were parents' consanguinity was recorded in(34.6%) of cases. That mean positive consanguinity plays an important role in most risk factors for CP in Minia governorate.

CP classification according gestational age

Cerebral palsy children were classified according to their gestational ages: Preterm gestational age below 37weeks

was46.6%, full term: gestational age between 37-42 weeks was 50.2%, and post term; gestational age over 42 week was 3.2%. The birth weight of CP was recorded as extremely very low birth weight, low birth weight, normal birth weight and high birth weight as 3.6 %, 26.5 %, 69.2 % and 8% respectively. Among the health disadvantages associated with low birth weight, there were cognitive deficits, motor delays, cerebral palsy, and other behavioral and psychological problems (Reichman, 2005). The world health Organization (WHO) has reported that the prevalence of LBW infants is 15.5% or approximately 20 million of all births and common in developing countries. The LBW rate was 16.5% in developing countries and 7% in developed countries (Sutan *et al.,* 2014). Cerebral palsy children were classified according to their onset into Prenatal, Perinatel and Postnatal which were 6.3%, 51.8% and 41.9% respectively from the total cases. It was observed that the most risk factors were the perinatal and low birth weight risk factors so; we assume that CP incidence can effectively be lowered by improving the pregnancy monitoring and by increasing the standards of delivery room, delivery teams and neonatal intensive care units. Increase of prenatal care and hazards of consanguinity marriages suggested medical and educational intervention strategies. Such as, family planning, vaccines, universal literacy, genetic counseling, educational programs, and infant health education in the areas of infections, trauma, and sudden infants' death syndrome. Medical interventions include the use of ultrasound in early pregnancy. Our results revealed that there were 52.6% delivered normally and 47.4% were delivered by cesarean section. Regarding to these results, the incidence of CP children who were delivered normally was higher due to low economic status, they do many trials for normal labor through physicians in private clinics without appropriate equipments and a lot of people still have fear from cesarean section. The results of this study contradict with Clark and Hankins, (2003). Who concluded that "despite a 5-fold increase in the rate of cesarean section based, in part, on the electronically derived diagnosis of fetal distress.

CP classification according type

The current study revealed that spastic CP represented 68%., deyskinetic CP was 18.6% ataxic CP was 13.4 % and hypotonic was 10.7 % this comes in agreement with Blair and Watson (2006) who reported that spasticity was typically cited as the predominant motor type, occurring in 77% to 93% of CP cases, dyskinesia in 2% to 15%, and ataxia in 2% to 8%. Yasin and Abdalazim, (2016) also reported that spastic CP was 72.5% dyskinetic CP was 16%, ataxic CP was 7% hypotonic CP was 4.5% diplegla percentage was 40.9%- 54.9% in the cases. Which mean that spastic CP is most common type.

CP classification according to evaluation by

1-GMFCS

In this study using GMFCS showed that 4.7 % of children were level 1, 31.6% were level II.37.2 % were level III, 25.7 % were level IV, and. 8% were level V. In Swedish data the children's gross motor function was 32% at level I, 29% at level II, 8% at level III, 15% at level IV, and 16% at level V as measured by the GMFCS (Himmelmann et al., 2006). (Lowing et al., 2015) Stated that all five levels within the GMFCS were represented with 22% children were level I, 26% were level II, 16% were III, 17% were level IV and 19% of the children were

level V. and also this come in agree with Yasin and Abdalazim, (2016) who reported that the children's GMFCS was 9.5% at level I, 25% at level II, 31.5% at level III, 18.5% at level IV, and 15.5% at level V.

2-MACS

The MAC system was used in the study and revealed that 10.7% of children were level I, 31.2% were level II, 33.6 % were level III, 24.1 % were level IV and 0.4% were level V. and this differ from Yasin and Abdalazime, (2016) who reported that level I was 20.3%,level II was 22.9%,level III was 35.14%, level IV was 21.62% and level V was zero. These mean that there is significant relation between subtypes of CP and MACS level.

3-Viking

According to Viking speech scale which used in the study and showed that 32.8% were level I, 33.6% were level II, 19.8% were level III, and 13.8 % were level IV. This near to Yasin and Abdalazime, (2016) who reported that level I was 20.3%,level II was 22.9%,level III was 35.14% and level IV was 21.6%. These mean that there is significant relation between subtypes of CP and Viking speech scale.

4- GMFM

The main and standard deviation for GMFM score are (158.14) $\pm$59.1. And the 95% confidence interval for GMFM is given by 158.14 $\pm$3.72. Which means It's expected that 45% of the children under 18 years old in (minia)population were have GMFM score range from 144.42 to 161.86 and this lower than Yasin and Abdalazime,(2016) who reported that GMFM score ranged from 190 to 240. We observed those low scores in GMFCS, MACS, GMFM and Viking speech scale cauld be d due to decrease physical therapy services in the villages and rural places so; this research study recommended increasing physical therapy centers in rural areas and villages.

Classification of CP according to associated impairment

This study showed that 80.8% of CP children have associated disorders. Epilepsy was 72.7%, cognitive disorders were 45.5%, loss of vision was 6.3% and hearing impairment was 8.3%. And this agree with Serdaroglu et al, 2006 who reported that 25%- 80% of CP children had cognitive disorders and other problems (epilepsy; auditory, language and visual, chronic pain, gastrointestinal and nutritional) can also be seen, epilepsy occurs in between 15% and 55% off children and adults with CP. The study showed that there was a direct relationship between epilepsy and cognition. This could be explained by the fact that children with bilateral CP might suffer extensive brain injury including cortex, deep white matter and central nuclei and therefore they are liable to mental retardation and epilepsy. Hence, an early intervention by psychotherapy, physical and neurological examination with treatment of epilepsy prevents further progression of neuronal injury with subsequent cognitive impairment caused by uncontrolled seizures among those patients. The study showed that 4.3% of CP children had swallowing problems this is a low percent compared with (Reilly et al. 1996) who stated that more than one third (36.2%) of children were classified as having severe oral motor dysfunction, 21.3% had moderate oral motor dysfunction and 34% mild impairment.

Only 8.5% had no oral motor impairment according to their scores on the Schedule for Oral Motor Assessment. We assume that swallowing problem can effectively be lowered by life style changing in which making eating and swallowing more comfortable and early medical intervention can be used. The study showed that 15.4 % of CP children had a speech problem which is near to Geytenbeek, 2001 who stated that 28% of the children had speech problems. We assume that speech problem can effectively be lowered by increasing communication, interaction and socialization between CP children in the same session, educational program and speech therapy.

Recommendations

- Establish as software registry edition to facilitate registry
- Establish database for cerebral palsy patients all over Egypt with the participation of faculty of physical therapy, Cairo University and the Ministry of health.
- Increase community awareness about consanguinity marriages and cerebral palsy children in all forms of media.
- Increase physical therapy services in the villages and rural places by increasing physical therapy departments in units of family medicine.
- Raise community awareness about the risks of private clinics delivery.
- Increase community awareness of the importance of physical therapy for Make the ability of cesarean section in family units
- Increase number of private centers in the rural places.

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