# Establish registry of cerebral palsy in mit-ghamer city, Egypt

Shymaa Yasser<sup>1</sup>, Faten Abdelaziem<sup>2</sup>, Houda Eltallawy<sup>3</sup>

<sup>1</sup>BSc degree in Physical Therapy, Cairo University, Egypt.

 <sup>2</sup>Professor and Head of Physical Therapy Department for Growth and Developmental Disorder in Children and its Surgery, Faculty of Physical Therapy, Cairo University, Egypt.
 <sup>3</sup>Professor of Physical Therapy Department for Growth and Developmental Disorder in Children and its Surgery, Faculty of Physical Therapy, Cairo University, Egypt.

Surgery, Fucuny of Enysical Incrupy, Carlo Oniversity, Egypt.

**Abstract:** The cerebral palsy register is research information developed to facilitate the study of the distribution, prevalence and severity of cerebral palsy, the etiology and determinants of cerebral palsy, the effectiveness of prevention methods and to assist set up and evaluate services.

Aim: To establish data base about cerebral palsy in MitGhamer city.

Subject and methods: cerebral palsy children receiving physical therapyof both genders participated in the study and age ranged from6 month to15 years. All cerebral palsy children are from Mit-Ghamer and its villages. Cerebral palsy children collected from hospitals and private centers. Gross Motor Function Classification System Expanded and Revised (GMFCS-ER); Gross Motor Function Measure (GMFM), Manual Ability Classification System (MACS) and Viking Speech Scale (VSS) were used in assessment of cases.

**Results:** Spastic children represent 79.5%, hypotonic children represent 12.1%, dyskintic children represent 4.5% and ataxic children represent 3.8% of total cerebral palsy cases. Results from GMFCS, GMFM, MACS and VSS were recorded.

**Conclusion:** Spastic type has the highest frequency among cases and spastic quadriplegia is the most common type. According to GMFCS; Level 5 have the highest percentage, this means that the severity of the cases were high.

Keywords: Cerebral Palsy, MitGhamer, Registry.

# I. Introduction

Cerebral palsy is that the most common cause of severe disabilities in early childhood. The core symptom of CP is disorder of movement and/or posture, but is usually accompanied by other neurodevelopmental disorders or sensory issues, like disturbances of sensation, cognition, communication, perception, behavior and/or seizure disorders. The disorder contains a complex and poorly understood etiology. <sup>[1, 2]</sup>Cerebral palsy (CP) registers:appear to be appropriate tools for answering questions regarding the prevalence and characteristics of this common childhood disability <sup>[3]</sup>. The cerebral palsy register is research information developed to facilitate the study of the distribution, prevalence and severity of cerebral palsy, the etiology and determinants of cerebral palsy, the effectiveness of prevention methods and to assist set up and evaluate services.<sup>[4]</sup> Registers are population databases issuing from multiple sources, relying on a clear definition and inclusion and exclusion criteria of CP, and requiring a mix of skills with the collaboration of obstetricians, pediatricians, and epidemiologists. In Europe alone there are 18 different registers or population data collections on CP, and collaborative research efforts exist through European network. Data collection on CP has also been done in Australia (register), the United States (surveys), and Canada (register). Beside monitoring trends, other public health contributions of CP registers might be to reduce the frequency of CP and to improve the quality of life of children with CP. CP registers are useful to clinicians by enabling them to identify subgroups of children requiring specific etiologic investigations, and also to provide more accurate information to the parents of children with CP<sup>[3]</sup>. Gross Motor Function Classification System Expanded and Revised (GMFCS-E&R) has been shown to be a reliable and valid method for classifying function among children with CP and is widely used in clinical settings. The GMFCS-E&R is a 5-level scale that classifies GMF according to degree of independence in ambulation, transfer and postural stability<sup>[5]</sup>. The Gross Motor function measure (GMFM) is a valid tool to assess motor function in children with CP. It measures gross motor function throughout lying and rolling, crawl and kneel, sitting, standing, and walk-run-jump activities <sup>[6]</sup>.MACS describes how children typically use their hands to handle objects within the home, school, and community settings (what they do), instead of what's familiar to be their best capability <sup>[7]</sup>. The Viking Speech Scale is developed for use with children aged 4 years and above. The scale has four levels. The scale is ordinal, there is no expectation that the differences between the levels are evenly spaced, or that children will be spread evenly across the levels<sup>[8]</sup>. The Viking Speech Scale (VSS) is adopted as the single measure of speech in epidemiological surveillance. supplemented with additional information on cognition, sensation, and manual ability <sup>[9]</sup>. Purpose of the study: is to establish data base about cerebral palsy in MitGhamer city, Egypt.Significance of the study: that registry provides a coordinated data base collection system for CP. CP registry will improve research quality by providing large population sample and describe our need for social and health services for people with CP. The incidence of cerebral palsy 2-2.5 per 1000 live births in developed countries <sup>[10]</sup>. Cerebral palsy represents 67% of the severe motor disabilities in childhood <sup>[11]</sup>. It is one of the three most common lifelong developmental disabilities <sup>[12]</sup>.

### **II.** Subject and methods

All CP children of both genders participated in the study and theirages ranged from6 month to15 years and were 132 cases.All CP children are from Mit-Ghamer and its villages.Children collected from :( Mit-GhamerCentral Hospital,Health Insurance Hospital in Mit-Ghamer,Units of family medicine in villages of Mit-Ghamer city and Private physical therapy centers deal with cerebral palsy).

Ethics: consent approval from parent and approval letter from faculty of physical therapy to begin the study.

This study last three months using Gross Motor function classification system (GMFCS –E&R) and also the MACS feature a five-levelordinal scale that reflects, in a decreasing order, the extent of independence and functionality of children with CP. Fora six year-old child, grade I (GMFCS-E&R) classification indicate the ability to move without any restrictions; level II indicates limitations in gait in outdoor settings; and level III is reserved for those who need help so as to move about. At level IV, the patient needs assistive technology equipment to move, and at level V, the child demonstrates severe movement restrictions, even with the aid of state of the art technology. Within the MACS, despite age, children who are able to simply manipulate objects are classified as level I, and those who handle objects poorly belong in group II. Level III children, in turn, manipulate objects with difficulty, requiring facilitate or adaptation of the activity, whereas those in level IV perform manual activities with restricted success, and below constant supervision. Finally, level V includes children with severely compromised manual abilities who need complete assistance <sup>[13]</sup>.

The GMFM, as a criterion-referenced assessment, was administered to quantitatively measure gross motor function. The GMFM consists of 88 items related to gross motor tasks clustered into five dimensions: lying and rolling (17 items); sitting (20 items); crawling and kneeling (14 items); standing (13 items); and walking, running, and jumping (24 items). Items are scored ordinal scale (scale from 0–3). Scores for each dimension are expressed as a percentage of the maximum possible score for that dimension. A total score is obtained by adding the scores <sup>[14]</sup>. The Viking Speech Scale (VSS) has been developed to classify children's speech production. The ease with which children canmake themselves understood using other methods of communication is scored using different scales. It has four levels are level I speech is not affected by motor disorder, level II speech is imprecise but usually understandable to unfamiliar listeners, level III speech is unclear and not usually understandable to unfamiliar listeners out of context. Level IV. No understandable speech<sup>[8]</sup>.

#### Statistical analysis

Data were analyzed using SPSS computer package version 11.5 (SPSS, Chicago, IL, USA). Data were presented as mean  $\pm$  SD for normally distributed. For qualitative data, chi-squared ( $\chi^2$ ) was used for comparisons between groups. Spearman's correlation coefficient was used to correlate various variables in the studied groups. For all tests P < 0.05 was considered to be statistically significant and P<0.01 the correlation was considered highly significant.

## III. Result

The number of cerebral palsy children receives physical therapy services were 132 children represent about (0.6per 1000 live birth). Characteristics of the cases ranged from 6 month to 180 month (15 years old). 78 boys which represent 59.1% (0.38 per 1000 birth) and 54 girls which represent 40.9% of the cases (0.26 per 1000 birth). Rural resident children were 92 represent 69.7% (0.45 per 1000 birth) and urban resident children were 40 represent 30.3% of the cases (0.19 per 1000 birth). According to gestational age; 44 children were preterm represent 33.3% (0.21 per 1000 birth), 76 children were full-term represent 57.6% (0.37 per 1000 birth) and 12 children with unknown gestational age represent 9.1% (0.05 per 1000 birth). According to type of delivery; 75 children were delivered normal spontaneous labor represent 56.8% (0.36 per 1000 birth) and 57 children were delivered through caesarian section represent 43.2% (0.28 per 1000 birth). According to presence of plurality; 13 children were in plurality pregnancies represent 9.8% (0.06 per 1000 birth) and 119 children were singleton represent 90.2% (0.58 per 1000 birth).Birth weight show the following: 3 children were extremely low birth weight (ELBW) represent 2.3%, 25 children were very low birth weight (VLBW) represent 18.9%, 47 children were low birth weight (LBW) represent 35.6%, 32 children were normal birth weight (NBW) represent 24.2%, 4 children were high birth weight (HBW) represent 3% and 21 children with unknown birth weight represent 15.9%. Parent consanguinity show that 50 parents having positive consanguinity represent 37.9% and 82 parents having negative consanguinity represent 62.1%.

Order of the child among his brothers show the following: 74 children were the first child represent 56.1%, 26 children were the second child represent 19.7%, 11 children were the third child represent 8.3%, 15 child were the fourth child represent 11.4%, 5 children were the fifth child represent 3.8% and 1 child was the sixth child represent 0.8%.

						Reviscu.						
GMFCS	Level 1		Level 1 Level 2		Level 3 Level		el 4 Level 5		χ2	р		
	Ν	%	Ν	%	Ν	%	Ν	%	Ν	%		
age												
6m - <2y	5	35.7%	8	34.8%	12	33.3%	7	35.0%	8	20.5%	20.902	0.182
2y - <4y	4	28.6%	9	39.1%	14	38.9%	8	40.0%	8	20.5%		
4y - <6y	2	14.3%	5	21.7%	5	13.9%	3	15.0%	8	20.5%		
6y - <12y	2	14.3%	1	4.3%	4	11.1%	2	10.0%	7	17.9%		
12y - 15y	1	7.1%	0	0.0%	1	2.8%	0	0.0%	8	20.5%		

 Table (1): Level of impairment according to Gross Motor Functional Classification System Expanded and Revised:

The age group from (12y to 15y) has the lowest number in cerebral palsy cases. 10 children were in that group represent 7.6%. Eight children were at level 5.

Gross Motor Function Measure (GMFM) assesses Function of Cerebral Palsy Children in 5 Areas According to age grouping (Table 2):

<b>CP</b> type	SH	SD M±SD	SQ M±SD	DK	AT	HY M±SD	t	Р
	M±SD	N=9	N=16	M±SD	M±SD	N=8		
GMFM	N=7			N=2	N=1			
Lying	63.24 ±	68.63 ±	41.99 ±	49.02 ±	88.23 ±	56.86 ±	2.907	.027
	23.97	11.32	22.35	13.87	.00	21.69		
Sitting	47.50 ±	38.74 ±	17.89 ±	15.00 ±	75.00 ±	33.57 ±	4.382	.003
_	27.98	19.41	20.43	14.14	.00	18.32		
Kneeling	26.98 ±	$7.14 \pm 11.33$	$4.13\pm9.15$	5.95 ±	36.90 ±	14.62 ±	3.475	.012
_	22.62			8.41	31.99	19.21		
Standing	11.96 ±	$.64 \pm 1.28$	$1.62\pm5.93$	$.00 \pm .00$	3.85 ±	$2.56 \pm 4.68$	2.500	.050
_	11.99				5.44			
Walking	$3.93 \pm 5.58$	$.00 \pm .00$	$.00 \pm .00$	$.00 \pm .00$	$.00 \pm .00$	.20 ± .52	3.344	.015
total	30.72 ±	$23.03 \pm 8.17$	$13.13 \pm 9.95$	13.99 ±	40.80 ±	21.56 ±	4.064	.005
	16.48			7.28	7.49	11.96		

 Table (2a): GMFM of the age group from 6m to 2 y: mean, standard deviation, t test and p value

Result of the age group from 6m to 2 y: using ANOVA test revealed that each area has p value  $\leq 0.05$  that differences between means are statistically significant.

Table (2b): GMFM of age group 2y to 4y: mean, standard deviation, t test and p value

CP type	SH	SD	SQ	DK	AT	HY	t	Р
	M±SD	M±SD	M±SD	M±SD	M±SD	M±SD		
GMFM	N=7	N=9	N=16	N=2	N=1	N=8		
lying	$66.10 \pm$	$80.82 \pm$	$67.64 \pm$	43.13 ±	74.50 ±.	$66.90 \pm$	1.1	.336
	19.92	9.29	23.00	5.54		29.69	83	
sitting	46.19 ±	$69.07 \pm$	$45.93 \pm$	$16.67 \pm$	56.66 ±.	53.33 ±	2.0	.093
	24.15	13.44	25.16	7.06		31.28	61	
kneeling	27.21 ±	$40.73 \pm$	24.25 ±	4.76 ±	54.76 ±.	36.60 ±	1.6	.175
	18.12	16.17	20.43	6.73		31.73	37	
standing	$16.48 \pm$	$16.62 \pm$	$10.09 \pm$	$1.28 \pm$	30.76 ±.	$21.46 \pm$	1.5	.199
	11.64	10.87	10.65	1.81		21.18	47	
walking	4.16 ±	6.94 ±	$2.08 \pm$	$.00 \pm .00$	6.94 ±.	5.54 ±	1.4	.238
	4.67	5.93	4.24			6.95	26	
TOTAL	$32.03 \pm$	$42.84 \pm$	30.00 ±	13.17 ±	44.72 ±.	36.77 ±	1.6	.182
	15.05	9.40	15.19	1.29		23.34	07	

Result of age group from 2y to 4y: using ANOVA test revealed that each area has p value  $\geq 0.05$  that indicate the differences between the means are not statistically significant. The standard deviation of ataxic group does not exist in this age group as only one case of ataxic cerebral palsy exists.

CP type	SH	SD	SQ	DK	t	Р
	M±SD	M±SD	M±SD	M±SD		
GMFM	N=3	N=8	N=10	N=2		
lying	$83.00 \pm 1.13$	$84.06 \pm 14.42$	$62.55 \pm 22.80$	$53.92\pm20.80$	2.964	.058
sitting	$77.22 \pm 3.47$	$72.08 \pm 21.25$	$43.67 \pm 25.44$	$24.99 \pm 11.79$	4.749	.012*
kneeling	$53.17 \pm 17.87$	$64.58 \pm 22.06$	$27.14 \pm 19.25$	$17.85 \pm 8.41$	6.643	.003*
standing	$35.04 \pm 16.28$	$51.60 \pm 18.96$	$15.38 \pm 13.99$	$7.69 \pm 7.25$	9.040	.001*
walking	$19.61 \pm 13.67$	$26.04 \pm 16.31$	$5.14 \pm 6.52$	$.69 \pm .98$	5.786	.006*
TOTAL	$53.61 \pm 9.28$	$59.67 \pm 17.51$	$30.77 \pm 17.02$	$21.03 \pm 9.85$	6.334	.004*

Table (2c): GMFM of age group from 4y to 6y: mean, standard deviation, t test and p value

Result of age group from 4y to 6y: using ANOVA test revealed that four areas have p value  $\leq 0.05$  that indicate the differences between the means are statistically significant except lying area. There is no ataxic or hypotonic cerebral palsy in this age group.

**Table (2 d):** GMFM of age group from 6y to 12y:

CP type	SH M±SD	SD M±SD	SQ M±SD	AT	HY	t	Р
	N=4	N=2	N=7	M±SD	M±SD		
GMFM				N=2	N=1		
lying	$92.15\pm9.19$	96.07 ±	50.97 ±	$71.56 \pm 31.89$	$92.15\pm0.00$	2.450	0.108
		2.77	31.02				
sitting	$79.58 \pm 9.85$	87.50 ±	30.71 ±	$57.50 \pm 34.18$	$68.33 \pm 0.00$	2.899	0.073
-		5.90	33.90				
kneeling	$69.64 \pm 11.73$	83.33 ±	14.96 ±	$35.71 \pm 16.84$	$57.14 \pm 0.00$	5.043	0.015*
-		16.84	30.29				
standing	$46.15 \pm 13.57$	64.10 ±	8.06 ±	$19.23 \pm 9.07$	$17.94 \pm 0.00$	4.607	0.020*
		36.26	19.10				
walking	$28.82 \pm 11.70$	50.00 ±	6.55 ±	$3.47 \pm 4.91$	$4.16\pm0.00$	2.488	0.104
-		47.14	17.32				
TOTAL	$63.27 \pm 6.27$	76.20 ±	22.25 ±	$37.49 \pm 19.38$	$47.94 \pm 0.00$	4.164	0.027
		21.78	24.56				

Result of age group from 6y to 12y: using ANOVA test revealed that kneeling and standing area has p value  $\leq 0.05$  that indicate the differences between the means are statistically significant. There is no dyskinetic cerebral palsy in this age group.

	<pre></pre>		~	~
SP type	SH	SQ	t	Р
	M±SD	M±SD		
GMFM	N=1	N=9		
lying	$98.03 \pm 0.00$	$26.79 \pm 23.49$	8.279	0.021*
sitting	$93.33 \pm 0.00$	$12.41 \pm 26.69$	8.272	0.021*
kneeling	$88.09 \pm 0.00$	$7.94 \pm 23.81$	10.202	0.013*
standing	$76.92\pm0.00$	$4.27 \pm 12.82$	28.900	0.001*
walking	$69.44 \pm 0.00$	$1.85 \pm 5.55$	133.317	< 0.001*
TOTAL	$85.16\pm0.00$	$10.65 \pm 18.40$	14.763	0.005*

**Table (2e):** GMFM of age group from 12y to 15y:

This age group has only quadriplegic and hemiplegic cerebral palsy types and using ANOVA test revealed that each area has p value  $\leq 0.05$  that indicate the differences between the means are statistically significant.

 Table (3): Correlation between gross motor function classification system (GMFCS) and gross motor function measure (GMFM):

GMFCS	$age = 6m - \langle 2y \rangle$		$age_=2y - \langle 4y \rangle$		$age_=4y - <6y$		age = $6y - <12y$		age = 12y - 15y		
GMFM	r	Р	r	Р	r	Р	r	Р	r	Р	
lying	-0.838	0.000	-0.898	0.000	-0.889	0.000	-0.915	0.000	-0.721	0.019	
sitting	-0.790	0.000	-0.862	0.000	-0.915	0.000	-0.918	0.000	-0.712	0.021	
kneeling	-0.674	0.000	-0.782	0.000	-0.929	0.000	-0.946	0.000	-1.000	0.000	
standing	-0.577	0.000	-0.771	0.000	-0.832	0.000	-0.957	0.000	-1.000	0.000	
walking	-0.340	0.032	-0.614	0.000	-0.885	0.000	-0.960	0.000	-1.000	0.000	
TOTAL	-0.818	0.000	-0.859	0.000	-0.924	0.000	-0.944	0.000	-0.705	0.023	

The Spearman correlation coefficients for the correlations between GMFCS levels and GMFM total score. The GMFCS level was strongly associated with the GMFM total score. There is a strong relation between GMFCS and GMFM as P value  $\leq 0.05$  that difference between means are statistically significant and correlation coefficient is a strong negative linear relationship.

## **IV. Conclusion**

This study has great importance aiming to establish a data base about cerebral palsy. This will help to improve health services and awareness about cerebral palsy and establish a registry about cerebral palsy in Egypt. This study is not only counting cases but also using ways of assessment like GMFCS-E&R and GMFM. So, following studies may be done to assess physical therapy services and as a follow up of cases. This study is limited to MitGhamer city and its villages.so many study may be done to cover whole areas in Egypt. This paper only focuses on GMFCS-E&R and GMFM and correlation between them.

#### References

- [1] S.Thygesen, M. Olsen, J.ØstergaardandH.Sørensen .Respiratory distress syndrome in moderately late and late preterm infants and risk of cerebral palsy: a population-based cohort study. *BMJ Open* 2016(6) e011643.10.1136/2016-011643.
- D.Hurley,T.Sukal-Moulton, D.Gaebler-Spira, K.Krosschell.L.Pavone.A.Mutlu.P.Dewaldand E.Msall. Systematic Review of Cerebral Palsy Registries/Surveillance Groups: Relationships between Registry Characteristics and Knowledge Dissemination. Int J Phys Med Rehabil 2015, 3: 266.
- C. Cans, G.Surman, V. McManus, D.Coghlan, O.Hensey and A. Johnson .Cerebral palsy registries. *SeminpediatrNeurol.Mar*, 2004, 11(1):18-23.
- [4] Australian Cerebral Palsy Register .Report of the Australian Cerebral Palsy Register, Birth Years 1993–2006. Sydney: *Cerebral Palsy Alliance Research Institute* (2013).
- [5] R. Benedicta, J. Patza, M. Maennera, C. Arnesona, M.Allsoppd, N. Doernbergd, K.Braund, R. Kirbye and M. Durkina. Feasibility and reliability of classifying gross motor function among children with cerebral palsy using population-based record surveillance. *Paediatric and Perinatal Epidemiology*, 25, 2010, 88–96.
- [6] S.Lee, J.Shim, K. Kim, J. Moon and M. Kim. Gross Motor Function Outcome after Intensive Rehabilitation in Children with Bilateral Spastic Cerebral Palsy. Ann Rehabil Med 2015; 39(4):624-629.
- [7] A .Eliasson,L. Krumlinde-Sundholm, B.Rösblad,E.Beckung, M .Arner, M .Ohrvall and P.Rosenbaum.The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability.*Developmental Medicine and Child Neurology*. 2006 Jul; 48(7):549-54.
- [8] L. Pennington, N. Miller, S. Robson and N. Steen. Intensive speech and language therapy for children with cerebral palsy: A systems approach. *Developmental Medicine and Child Neurology*.(2010).52, 337-344.
- [9] D.Virella, L. Pennington, G.Andersen, M.Andrada, A.Greitane, K.Himmelmann, A.Prasauskiene, G.Rackauskaite, J. De La Cruz, A.Colver and On Behalf Of Surveillance Of Cerebral Palsy In Europe Network. Classification systems of communication for use in epidemiological surveillance of children with cerebral palsy. *Developmental Medicine & Child Neurology* 2016, 58: 285–291.
- [10] M. Shevell and J.Bodensteiner. Cerebral palsy: defining the problem .*SeminPediatr Neurol*. (2004). 11(1):2-4.
- [11] A.MacLennan.A template for defining a causal relationship between acute intrapartum events and cerebral palsy: International consensus statement.International Cerebral Palsy Task Force. Aust N Z J ObstetGynaecol. (2004). 40:13-21.
- [12] C.Sankar and N.Mundkur. Cerebral palsy-definition classification, etiology and early diagnosis. *Indian J Pediatr.Oct*(2005). 72(10):865-8.
- [13] P.Chagas, E. Defilipo, R.Lemos, M.Mancini, J.Frônio and R.Carvalho. Classification of motor function and functional performance in children with cerebral palsy. *Rev Bras Fisioter*. 2008; 12(5):409-16.
- [14] E.Park and W. Kim. Relationship between the Gross Motor Function Classification System and Functional Outcomes in Children with Cerebral Palsy. *Indian Journal of Science and Technology*. 8(18), 2015.