### Improving the Care Provided to Hemiplegics Cerebral Palsy Children by Their Family Caregivers: An Intervention Study

Eman Shokry Abd Allah<sup>1</sup>, Samah El Awady<sup>2</sup> and Howyida S. Abd EL Hameed <sup>3</sup>

<sup>1-3</sup>Community Health Nursing and <sup>2</sup>Pediatric Nursing Departments Faculty of Nursing, Zagazig University <sup>3</sup>Faculty of Nursing Benha University emanshokry2012@yahoo.com

Abstract: Cerebral palsy (CP) is a form of brain damage that constitutes a leading cause of physical disability in childhood. Caregivers' perceptions of their child's needs are likely to have substantial impact on the success of rehabilitative management. The aim of this study was to evaluate the effectiveness of a health teaching intervention to family caregivers in improving their knowledge and practices towards care of their children suffering from hemiplegic CP. Design: A single group quasi-experimental design was utilized for this study (pre-post test format. Setting: This study was conducted at homes of the study sample that was selected from all institutions for social rehabilitation at Zagazig Governorate (3 institutions). Subjects: The sample consisted of (50) all family caregivers and their children aged from 3 to less than 6 years. Tools An interview questionnaire and an observation checklist were used for data collection before and after implementation of a health teaching program developed by the researchers based on collected data and related literature. The study lasted from January to June 2011. Results showed many areas of deficient knowledge among family caregivers at the pretest, with 9 (18%) caregivers having satisfactory knowledge. This increased to 88% at the posttest (p < 0.001). Caregivers' adequate reported and observed practices increased from 22% and 26% to 60% and 84%, respectively (p < 0.001). Conclusion The improved knowledge was an independent positive predictor of the scores of practice. Thus, the educational program was effective in improving the knowledge and practices of CP children's parents. It is recommended to implement this program in many settings to support its effectiveness, and to test it in a randomized clinical trial to confirm the findings.

[Eman Shokry Abd Allah, Samah El Awady and Howyida S. Abd EL Hameed. Improving the Care Provided to Hemiplegics Cerebral Palsy Children by Their Family Caregivers: An Intervention Study. *J Am Sci* 2012;8(2):730-737]. (ISSN: 1545-1003). http://www.jofamericanscience.org. 102

Key Words: Cerebral Palsy, Caregivers, Knowledge, Practice, Educational program.

#### 1. Introduction

Cerebral palsy (CP) refers to a form of brain damage that can severely affect motor control, coordination, speech and complex thought. In most cases, CP develops during pregnancy as a result of some trauma that injures the brain in-utero. Approximately 10 to 20% of children with CP acquire it after birth, typically from brain damage sustained in the first few months or years of life. In such cases, the disorder may result from brain infections like bacterial meningitis or viral encephalitis, or from head trauma sustained from an accident, fall, or inflicted injuries like the shaken baby syndrome. However, in many times no specific cause can be identified (Dumas et al., 2008). Depending on the severity of the case, the condition will likely be diagnosed between the ages of nine months and five years old (Shevell et al., 2003).

Cerebral palsy is a leading cause of physical disability in childhood with 90% of affected children sustaining damage or malformation to their developing brain during the antenatal period *(Pellegrino, 2007)*. Many children with CP are been

cared at homeis a tough responsibility. Brain damage makes everything the child does more difficult and in severe cases, can make him/her totally dependent upon others for every activity of daily living. The child may need to be dressed, fed, bathed, stimulated and taken to more medical appointments than children without CP. Moreover, the child is likely to need special <u>exercises</u> and treatments as often as every day (*Steven et al., 2009*).

When a child is diagnosed with cerebral palsy, parents may feel overwhelmed as they try to establish a comprehensive treatment regimen while dealing with the emotional effects of the diagnosis. So, early intervention to provide appropriate medical, educational, and family support services is of great importance, to achieve independence as much as possible in activities of daily living (ADLs) for CP children, in consistence with the right of the disabled child to have special social, health, psychological, and rehabilitation care in the society (*Cohen and Naimark*, 1991).

Nursing has a leading role in the care for CP children. An important aspect of this role is to

encourage self-care by urging the child to participate in ADLs, facilitating communication, seeking referrals for corrective lenses and hearing devices to decrease sensory deprivation related to vision and hearing losses, to help promote a positive self-image in the child. At the same time, the nurse should promote optimal family functioning, prepare the child and family for procedures, treatments, appliances and surgeries if needed, assist in multidisciplinary therapeutic measures designed to establish locomotion, communication and self-help, gain optimal appearance and integration of motor functions. Additionally, the nurse role involves encouraging the family to seek appropriate functional, adaptive and vocational training for the child (Davis et al., 2010).

#### Significance and aim of the study

Caregivers' perceptions of their child's needs and of efforts related to the daily care of their child are likely to have substantial impact on the selection and success of the child's rehabilitative management (Hwang et al., 2011). Meanwhile, it is important to remember that every child with CP is different and will have his/her own set of disabilities and obstacles to overcome. As a result, a unique education program will need to be designed, tailored to each child's individual needs. It is also important for parents to work with their children at home and implement the same principles so they can learn and grow in every aspect of their lives (Dumas et al., 2008). Although many studies have addressed parenting interventions for CP children, still more research is needed in this area (Whittingham et al., 2011).

The aim of this study was to evaluate the effectiveness of a health teaching intervention to family caregivers in improving their knowledge and practices towards care of their children suffering from hemiplegic CP. It was hypothesized family caregivers' knowledge and practices towards care of hemiplegic CP children will significantly improve after implementation of this custom-tailored intervention.

#### 2. Subjects and Methods Research design and setting:

A single group quasi-experimental design with pre-post assessment was utilized for carrying this study. The work was done at the homes of CP children selected from all three institutions for social rehabilitation at Zagazig Governorate. These are the main institutions that provide follow-up care and rehabilitation for disabled children with cerebral palsy in this Governorate. They include the Social Rehabilitation Center at AL-Sayadeen, the largest one, offering social, medical and occupational training for children, and providing services all weekdays except Friday; Nour Al-Hayat Association, providing preventive services as community council about disabilities and a nursery school for disabled children; Physiotherapy Clinic at Al-Mabarra hospital and Rheumatic and Rehabilitation outpatient clinics at Zagazig insurance hospital.

### Study subjects:

The study was carried out on a convenience sample of family caregivers of CP children. The inclusion criteria were being a main caregiver (coliving with the child and providing daily care for him/her) of a 3-6 years old child suffering from hemiplegic CP, and who is enrolled in one of the three selected institutions in Zagazig. A total of 50 caregivers fulfilled these criteria and were included in the study. These were 20 from the Social Rehabilitation Center at AL-Sayadeen, 15 from Nour Al-Hayat Association, and 15 from Al-Mabarra hospital and Rheumatic and Rehabilitation outpatient clinics at Zagazig insurance hospital.

#### Data Collection Tools:

The researchers developed an interview questionnaire form and an observation checklist for data collection. The structured interviewing questionnaire form included four parts. The first part was for the caregiver's demographic data such as age, sex, level of education, occupation, family income, marital status, residence, etc. The second part was for CP child's demographic and health characteristics such as age, sex, mode of feeding, primitive reflex, etc.

The third part assessed family caregivers' knowledge of hemiplegic CP through a series of closed questions covering CP definition. manifestations, causes, importance of early detection, warning signs necessitating medical advice, role of the family in early detection, positioning child/ pressing mandible during feeding, general hygiene and dental care for child, changing position during sleep, and training child for continence. For each question, a correct response was scored 1 and the incorrect zero. For each area of knowledge, the scores of the items were summed-up and the total divided by the number of the items, giving a mean score for the part. These scores were converted into a percent score. Knowledge was considered satisfactory if the percent score was 50% or higher and unsatisfactory if less than 50%.

The fourth part of the interviewing form was intended to assess family caregivers' reported practices concerning combing child's hair and cleaning nails, training for continence, sleep, and child safety at home. Each area was assessed by a set of steps, and the caregiver was asked about the steps whether done or not done. The items reported to be done correctly were scored "1" and the items not done or incorrectly done were scored "0." For each task, the scores of the items were summed-up and the total divided by the number of the items, giving a mean score for the part. These scores were converted into a percent score. The reported practice was considered adequate if the percent score was 60% or higher and inadequate if less than 60%.

#### **Observation checklist:**

This checklist was used to assess the care provided by family caregivers to their hemiplegic CP children at home. It covered the tasks of feeding the child, precautions to avoid aspiration, and personal hygiene including bathing, clothing, and dental care. Each task was assessed by a set of steps, and the caregiver was observed while performing the task. The items observed to be done correctly were scored "1" and the items not done or incorrectly done were scored "0." For each task, the scores of the items were summed-up and the total divided by the number of the items, giving a mean score for the part. These scores were converted into a percent score. The observed practice was considered adequate if the percent score was 60% or higher and inadequate if less than 60%.

### Validity and reliability:

The tools were translated into Arabic and then face and content validated by a panel of five experts: three from Community Health Nursing and two from Pediatric Nursing. All experts' recommendations were performed, and the tools were Finalized accordingly. The reliability of the reported and observed practice forms proved to be high, with Cronbach alpha coefficients 0.71 and 0.95, respectively.

#### Pilot study:

A pilot study was carried out on five family caregivers and their hemiplegic CP children, representing 10% of the main study sample. The aim was to test the practicability and feasibility of the tools and to determine the time needed for filling up the forms. Since no modifications were done in the tools, these subjects were included in the main study sample.

# Administrative design and ethical considerations:

The study protocol was approved by the Faculty of Nursing, Zagazig University. Official approvals to conduct the study were obtained through letters directed from the Faculty of Nursing to the Directors of the three institutions, explaining the study aim and procedures, along with its potential benefits. The researchers approached eligible caregivers individually, explained to them the study objectives and maneuvers, and invited them to participate. Those who agreed gave a written informed consent after being briefed about their rights to refuse or withdraw at any time with no negative consequences. They were assured that any information obtained would be confidential and used for the research purpose only. The study procedures could not inflict any harm on participants. **Fieldwork**:

The study was done during the period from January to June 2011. The work started with the assessment phase, where the researchers collected baseline data through interviews done at the homes of the family caregivers using the study tools. The interviewing time ranged from 45 to 60 minutes to assess family caregiver's knowledge and reported practice. Then, the researcher observed how the family caregivers cared for the child in the activities of feeding, bathing, dressing and teeth care using the observation checklist. This necessitated one or two visits to cover all activities.

Based on the collected data and the related literature, the researchers developed the health teaching program.

Then, at the implementation phase of the study, the researchers set a schedule to meet with each family individually, and conduct the training in a total of ten sessions. Each session ranged from 45 to 60 minutes. Different teaching methods and teaching materials were used in these educational sessions such as lectures, discussions, demonstrations, and role playing, along with the illustrative booklet prepared by the researchers.

The evaluation phase was done after completion of the ten sessions. The same interview sheet and observation checklist were used in this to assess the effectiveness of the program in improving family caregivers' knowledge and practices.

# Statistical analysis:

Data entry and statistical analysis were done using SPSS 16.0 statistical software package. Qualitative categorical variables were compared using chi-square test. In order to identify the independent predictors of family caregivers' knowledge, and reported and observed practice scores, multiple linear regression analysis was done after testing for normal distribution, normality, and homoscedasticity, and analysis of variance for the full regression models were done. Statistical significance was considered at *p*-value <0.05.

# 3. Results

Almost all family caregivers were females (94%), mostly mothers (66%), married (60%), not working (62%), with mean age of  $37.9\pm11.4$  years (Table 1). About half (54%) were illiterate or could just read and write. More than two-thirds (72%) of the family caregivers were living in rural areas, were having three or more children (68%), and their

monthly family income was more than 250 Egyptian Pounds (70%).

Concerning CP children, their mean age was  $4.5\pm 0.8$  years, with slightly more boys (60%). About one-fourth of them were firstborn children. The majority (82%) were on oral feeding, while 18% were on tube feeding. About two-thirds or more had the primitive reflexes, with 52% having all the three tested reflexes.

Table 3 indicates many areas of deficient knowledge among family caregivers at the pretest. This is most evident in the areas of CP definition and training child for continence, where the percentages of satisfactory knowledge were only 10% and 18%, respectively. In total, 9 (18%) caregivers had satisfactory knowledge before the program. Meanwhile, after implementation of the program, statistically significant improvements are shown in all the areas of knowledge, reaching 98% for the child positioning during feeding. However, still the area of definition remained the lowest (48%), although significantly improved. In total, 88% of the caregivers had satisfactory knowledge at the posttest.

Concerning caregivers' practice, Table 4 indicates that only about one third or less of the respondents had inadequate practices in almost all areas, whether reported or observed at the pretest. The only exceptions were the reported practice of child safety at home (76%), and the observed practice of precautions to avoid aspiration (48%). Overall, only 22% and 26% had adequate reported and observed practices, respectively, before the intervention. Meanwhile, the table indicates statistically significant improvements in all areas of reported and observed practices at the postintervention phase, reaching 94% for child safety at home. The percentages of adequate total reported and observed practices reached 60% and 84%, respectively.

Table 5 presents the results of multivariate analyses for the effect of the intervention program on caregivers' knowledge and practice. As regards knowledge, the table indicates that the intervention had the most important independent impact on knowledge scores improvement as indicated by the value of its standardized coefficient. Other independent factors that had a positive impact on knowledge scores were caregiver's older age, and higher education. The model explains 57% of the improvement in knowledge score as indicated by the value of its r-square. The other caregiver's sociodemographic characteristics had no significant influence on their knowledge score.

The model for reported practice indicates an independent positive impact of the intervention on its score. However, the improved knowledge was more

important as the value of its standardized coefficient indicates. The independent factors with positive impact on reported practice scores were the higher family income and less number of children. The model explains 53% of the improvement in reported practice score as indicated by the value of its rsquare. The other caregiver's socio-demographic characteristics had no significant influence on their reported practice score.

Regarding observed practice, the same table indicates that the intervention had an independent impact on observed practice scores improvement, and also through improved knowledge. Other independent factors that had a positive impact on observed practice scores were caregiver's urban residence and higher family income. Meanwhile, caregiver's higher education had a negative impact, which means that the improvement of observed practice was higher among those caregivers with lower levels of education. The model explains 42% of the improvement in observed practice score as indicated by the value of its r-square. The other caregiver's socio-demographic characteristics had no significant influence on their observed practice score.

#### 4. Discussion

This study was carried out to test the research hypothesis that family caregivers' knowledge and practices towards care of hemiplegic CP children will significantly improve after implementation of a custom-tailored educational intervention. The findings lead to acceptance of this hypothesis since the caregivers' knowledge as well as reported and observed practices demonstrated considerable ameliorations. Further, the multivariate analysis confirmed the independent effect of the intervention on the scores of these parameters.

The caregivers of CP children in the present study were mostly natural parents, with a majority being females, which is the situation usually reported in family caregiving of any chronic diseases, especially when the patient is a child (Brehaut et al., 2004). They also represent the prevalent characteristics of the community where the study was with high prevalence of illiteracy, done. unemployment, large number of children, and low income. These characteristics would certainly have a negative impact on the levels of their knowledge and practices, which turned to be deficient and inadequate before implementation of the study intervention.

**Table 1**: Demographic characteristics of caregivers (n=50)

	Frequency	Percent	
Age (years):			
<35	27	54.0	

Table 2: Socio-demographic and health characteristics of

35+	23	46.0
Range	18-60	
Mean±SD	37.9±11.4	
Sex:		
Male	3	6.0
Female	47	94.0
Caregiver relation:		
Mother	33	66.0
Father	2	4.0
Sister	3	6.0
Relative	6	12.0
Paid caregiver	6	12.0
Education:		
Illiterate	20	40.0
Read/write	7	14.0
Basic	5	10.0
Secondary	13	26.0
University	5	10.0
Marital status:		
Married	30	60.0
Single	4	8.0
Widow	14	28.0
Divorced	2	4.0
Job status:		
Not working	31	62.0
Working	19	38.0
Residence:		
Rural	36	72.0
Urban	14	28.0
Number of children:		
1-2	16	32.0
3-4	18	36.0
5+	16	32.0
Monthly family		
income (LE):		
<150	3	6.0
150-250	12	24.0
>250	35	70.0

CP children (n=50)	rapine and nearth char	
	Frequency	Percent
Age (years):		
<5	21	42.0
5+	29	58.0
Range	3.0-6.0	
Mean ± SD	4.5±0.8	
Sex:		
Male	30	60.0
Female	20	40.0
Birth order:		
1	14	28.0
2-3	20	40.0
4+	16	32.0
Range	1.0-8.0	
Mean ± SD	3.1±2.1	
BMI:		
Range	22.2-83.3	
Mean $\pm$ SD	49.4±15.9	
Feeding:		
Oral	41	82.0
Tube	9	18.0
Primitive reflexes		
present:		
Moro	37	74.0
Hand grasp	37	74.0
Tonic neck response	30	60.0
No. of primitive		
reflexes present:		
0	8	16.0
1	6	12.0
2	10	20.0
3	26	52.0

# Table 3: Caregivers pre-post intervention knowledge

		TI	ME			
Satisfactory knowledge (50%+)	Р	re	Po	ost	$X^2$	a value
about CP:	(n=	=50)	(n=	=50)	Test	<i>p</i> -value
	No.	%	No.	%		
Definition	5	10.0	24	48.0	17.53	< 0.001*
Manifestations	13	26.0	37	74.0	23.04	< 0.001*
Causes	13	26.0	31	62.0	13.15	< 0.001*
Importance of early detection	11	22.0	35	70.0	23.19	< 0.001*
Warning signs necessitating medical advice	13	26.0	43	86.0	36.53	< 0.001*
Role of the family in early detection	12	24.0	43	86.0	38.83	< 0.001*
Positioning child/ pressing mandible during feeding	39	78.0	49	98.0	9.47	0.002*
General hygiene and dental care for child	36	72.0	48	96.0	10.71	0.001*
Changing position during sleep	34	68.0	47	94.0	10.98	0.001*
Training child for continence	9	18.0	37	74.0	31.56	< 0.001*
Total knowledge:						
Satisfactory	9	18.0	44	88.0		
Unsatisfactory	41	82.0	6	12.0	49.18	<0.001*

(\*) Statistically significant at p<0.05

#### Table 4: Caregivers pre-post intervention practice

		Ti	me			
Practice		re =50)		ost =50)	X <sup>2</sup> Test	<i>p</i> -value
	No.	%	No.	<u> </u>	rest	
Reported:	110.	, 0	110.	, 0		
Combing hair and cleaning nails	8	16.0	33	66.0	25.84	< 0.001*
Training child for continence	11	22.0	24	48.0	7.43	0.01*
Child sleep	15	30.0	42	84.0	29.74	<0.001*
Child safety at home	38	76.0	47	94.0	6.35	0.01*
Total reported practice:						
Adequate (60%+)	11	22.0	30	60.0		

Inadequate (<60%)	39	78.0	20	40.0	14.92	<0.001*
Observed:						
Feeding child	15	30.0	40	80.0	25.25	< 0.001*
Precautions to avoid aspiration	24	48.0	40	80.0	11.11	0.001*
Personal hygiene: bathing	16	32.0	41	82.0	25.50	< 0.001*
Personal hygiene: clothing	16	32.0	38	76.0	19.48	< 0.001*
Personal hygiene: dental care	13	26.0	42	84.0	33.98	< 0.001*
Total observed practice:						
Adequate $(60\%+)$	13	26.0	42	84.0		
Inadequate (<60%)	37	74.0	8	16.0	33.98	< 0.001*

(\*) Statistically significant at p<0.05

Table 5: Best fitting multiple linear regression model for caregivers pre-post changes in caregivers' total knowledge	edge,
reported, and observed practice scores	

Pre-post changes in	Unstandard Coefficient		Standardized	t-test	<i>p</i> -value
scores of:	B	Std. Error	Coefficients	t-test	
Knowledge:					
Constant	-32.54	13.15		-2.47	0.015
Caregiver age	0.41	0.20	0.15	2.09	0.04
Caregiver education					
(reference: illiterate)	0.63	0.21	0.24	3.07	0.003
Intervention (reference: pre)	43.73	3.99	0.72	10.97	< 0.001
R Square = 0.57 Model ANOVA: F=27.51, p<0.001 Variables excluded by model: caregiver sex, m	arital status, job, resider	nce, income, numbe	r of children, child age,	sex, order	
Reported practice:					
Constant	-30.02	17.91		-1.68	.097
No. of children	-6.35	2.21	-0.21	-2.87	.005
Family income	11.29	2.95	0.28	3.83	< 0.001
	10 (1	1.00	0.00	2.63	.010
Intervention (reference: pre)	12.64	4.80	0.26	2.65	.010
Knowledge score	0.29	4.80 0.08	0.26	3.70	<0.001
Knowledge score R Square = 0.53 Model ANOVA: F=19.74, p<0.001 Variables excluded by model: caregiver age, se	0.29	0.08	0.37	3.70	
Knowledge score R Square = 0.53 Model ANOVA: F=19.74, p<0.001 Variables excluded by model: caregiver age, se <b>Observed practice:</b>	0.29 ex, residence, marital sta	0.08 tus, education, job	0.37	3.70	<0.001
Knowledge score R Square = 0.53 Model ANOVA: F=19.74, p<0.001 Variables excluded by model: caregiver age, se <b>Observed practice:</b> Constant	0.29	0.08	0.37	3.70	
Knowledge score R Square = 0.53 Model ANOVA: F=19.74, p<0.001 Variables excluded by model: caregiver age, se <b>Observed practice:</b>	0.29 ex, residence, marital sta	0.08 tus, education, job	0.37	3.70	<0.001
Knowledge score R Square = 0.53 Model ANOVA: F=19.74, p<0.001 Variables excluded by model: caregiver age, se <b>Observed practice:</b> Constant Caregiver education (reference: illiterate)	0.29 ex, residence, marital sta	0.08 tus, education, job	0.37 status, child age, sex, or	3.70 rder -1.80	<0.001
Knowledge score R Square = 0.53 Model ANOVA: F=19.74, p<0.001 Variables excluded by model: caregiver age, se <b>Observed practice:</b> Constant Caregiver education (reference: illiterate) Residence (reference: rural)	0.29 ex, residence, marital sta -24.85 -0.51	0.08 tus, education, job 13.80 0.24	0.37 status, child age, sex, or -0.19	3.70 rder -1.80 -2.10	<0.001 .075 .039
Knowledge score R Square = 0.53 Model ANOVA: F=19.74, p<0.001 Variables excluded by model: caregiver age, se <b>Observed practice:</b> Constant Caregiver education	0.29 ex, residence, marital sta -24.85 -0.51 17.29	0.08 tus, education, job 13.80 0.24 5.75	0.37 status, child age, sex, or -0.19 0.25	3.70 rder -1.80 -2.10 3.01	<0.001 .075 .039 .003

Variables excluded by model: caregiver age, sex, marital status, job status, number of children, child age, sex, order

Concerning the hemiplegic CP children, there were slightly more boys than girls, which goes in line with previous reports in the United states where the overall prevalence of CP had a boy/girl ratio: 1.4:1 (*Yeargin-Allsopp et al., 2008*). The majority were on oral feeding, with only 18% being tube-fed. These figures are very close to those reported by *Dahlseng et al. (2012)* in Norway, where the rate of tube feeding was 14% in CP children.

The mean body mass index (BMI) of the present study CP children was high, which is a relatively good sign indicating absence of under-nutrition, since BMI in addition to other anthropometric measures seem to represent accurate parameters for the assessment of malnutrition in patients with CP (*Karagiozoglou-Lampoudi et al., 2012*). Additionally, research has demonstrated that CP children who are ambulating have higher BMI compared to those who are not (Hurvitz et al., 2008).

The high prevalence of primitive reflexes among the CP children of the present study is an ominous sign, since these primitive reflexes are indicative of severe brain damage. This is especially evident with the Moro's reflex as indicated in the study of *Sohn et al. (2011)* in South Korea. They have also been claimed to have diagnostic and prognostic values in the evaluation of cognitive impairment *(Nicolson et al., 2011)*.

The current study revealed that the family caregivers of CP children had many knowledge gaps regarding the illness of their children. This is quite expected given the high prevalence of illiteracy among them, in addition to the low economic level. This is certainly reflected on their practices during caregiving, which were also found to be mostly inadequate. Similar low levels of knowledge and practice have been reported among caregivers of patients with various chronic diseases (*Bollinger et al., 2011; Rocker et al., 2012*). The findings highlight the real need of such parents to educational programs that respond to their needs as emphasized by *Desnous et al.* (2012) in France regarding the education needs of parents of epileptic children.

The implementation of the current study intervention led to significant improvements in caregivers' knowledge, which had a positive impact on their practices as shown in the multivariate analyses models. The improvements in caregivers' practices were more prominent in some areas as feeding, personal hygiene, sleep, and safety. The feeding problems of CP children are very common (Martinez-Biarge et al., 2012) and constitutes a real challenge for caregivers. The success of the intervention program in improving this area might be attributed to the fact that the training took into consideration the real educational needs of the caregivers, along with their socioeconomic factors. In congruence with this, Andrew et al. (2012) stressed that the feeding difficulties of CP children must be considered within the wider context of family and social circumstances.

Another practice related to CP child feeding that demonstrated improvement among the caregivers of the present study was related to the precautions to avoid aspiration as well as oral health. The intervention program succeeded to almost doubling the number of caregivers who showed adequacy of this practice. The importance of this lies in its serious consequences on the safety and the life of the child, since oropharyngeal and silent aspiration are very common in CP due to neurological impairment (Weir et al., 2011). The oral health is also critical in CP children since they suffer more gingival problems, tooth wear, oral mucosal disorders, and malocclusion (DU et al., 2010). Therefore, Oredugba and Akindavomi (2008) stressed the importance of improving caregivers' knowledge about the importance of dental care of disabled children.

Meanwhile, the current study revealed that the improvement in caregivers' practices in area of training in continence was less prominent, although significant. This might be related to the difficulties encountered in this task, which is even more accentuated in the neurologically impaired CP child. Added to this is the relatively young age of the study children, and the tolerance that many parents would express to the incontinent young child who is ill. In agreement with this, Wu (2010) clarified that toilet training and the achievement of urinary continence are culture-related. Hence, the decision to start toilet training should take consider parents' expectation of the extent of

independence of the child in toileting, as well as his/her developmental readiness.

Our intervention program was successful in improving caregivers' knowledge and practices regardless their socio-demographic characteristics. Nonetheless, the multivariate analysis showed that the caregivers having better education got more benefit from the knowledge part of the training, which might be explained by their more ability to understand some theoretical information regarding the disease. On the contrary, those with lower education benefited more from the practical aspects of the program, which does not need much intellectual abilities as knowledge does. Meanwhile, the urban residence, with lower number of children, and higher income had a positive impact on caregivers' practice, which is quite expected as these factors help caregivers to provide better care.

Therefore, the current study educational program proved to be effective for all socio-economic levels of the caregivers. This is certainly due to the fact that it was custom-tailored to needs, and considered these socio-economic elements. In congruence with this, *Adams et al. (2011)* found that caregivers in Bangladesh with minimal formal education, living in conditions of extreme poverty were able to change feeding practices after a short, low-cost training intervention, with highly positive consequences.

#### **Conclusion And Recommendations**

The study concludes that an educational program based on identified needs of hemiplegic CP children's family caregivers, and taking their socio-demographic characteristics into consideration can be effective in improving their knowledge and practices. The benefits of the program are achieved regardless the socioeconomic levels of these caregivers. However, these findings must take into account the study limitations. These are mainly regarding the study design, which is not true randomized trial, but rather a quasi-experimental design. Another limitation is the dependence on self-reporting in some of the caregivers' practices which were difficult to observe such as training on continence, sleep, and child safety. However, the improvement was demonstrated in both reported and observed practices, which may provide some validity to the self-reported results.

In view of the study findings, it is recommended to implement this program in many settings to support its effectiveness. It is also important to actively involve the family caregivers in the development of such programs, and to take their feedback into consideration for program amelioration. Meanwhile, it is suggested to test the effectiveness of the developed program in a randomized clinical trial to confirm the findings. **References** 

- Adams M.S., Khan N.Z., Begum S.A., Wirz S.L., Hesketh T., Pring T.R. (2011): Feeding difficulties in children with cerebral palsy: low-cost caregiver training in Dhaka, Bangladesh. Child Care Health Development, 37(6):757.
- Andrew M.J., Parr J.R., and Sullivan P.B. (2012): Feeding difficulties in children with cerebral palsy. Arch Dis Child Educ Pract Ed. 97:4 122-131.
- Bollinger L.M., Nire K.G., Rhodes M.M., Chisolm D.J., O'Brien S.H. (2011): Caregivers' perspectives on barriers to transcranial Doppler screening in children with sickle-cell disease. Pediatr Blood Cancer.; 56 (1):99-102.
- Brehaut J.C., Kohen D.E., Raina P., Walter S.D., Russell D.J., Swinton M., O'Donnell M., and Rosenbaum P. (2004): The Health of Primary Caregivers of Children With Cerebral Palsy: How Does It Compare With That of Other Canadian Caregivers? Pediatrics; 114(2): e182 -e191.
- Cohen C.P., and Naimark H. (1991): United Nations Convention on the Rights of the Child: Individual rights concepts and their significance for social scientists. American Psychologist; 46(1): 60-65.
- Dahlseng M.O., Finbråten A.K., Júlíusson P.B., Skranes J., Andersen G., Vik T. (2012): Feeding problems, growth and nutritional status in children with cerebral palsy. Acta Paediatr.;101 (1):92-8.
- Davis E., Shelly A., Waters E., Boyd R., Cook K., Davern M. (2010): The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. Child Care Health Dev; 36:63-73.
- Desnous B., Bourel-Ponchel E., Raffo E., Milh M., and Auvin S. (2012): [Assessment of education needs of adolescents and parents of children with epilepsy.] [Article in French]. Rev Neurol (Paris).
- DU R.Y., McGrath C., Yiu C.K., King N.M. (2010): Oral health in preschool children with cerebral palsy: a case-control community-based study. Int J Paediatr Dent.; 20(5):330-5.
- Dumas H.M., Watson K., Fragala-Pinkham M.A.P.T., Kathleen M., Gorton G.E., Mulcahey M.J., Tucker C.A. (2008): Using Cognitive Interviewing for Test Items to Assess Physical Function in Children with Cerebral Palsy, Pediatric Physical Therapy; 20(Issue 4): 356-362
- Hurvitz E.A., Green L.B., Hornyak J.E., Khurana S.R., and Koch L.G. (2008): Body mass index measures in children with cerebral palsy related to gross motor function classification: a clinic-based study. Am J Phys Med Rehabil.;87(5):395-403.
- Hwang M., Kuroda M.M., Tann B., and Gaebler-Spira D.J. (2011): Measuring Care and Comfort in Children with Cerebral Palsy: The Care and Comfort Caregiver Questionnaire. The American Academy of Physical Medicine and Rehabilitation; 3: 912-919.

- Karagiozoglou-Lampoudi T., Daskalou E., Vargiami E., and Zafeiriou D. (2012): Identification of feeding risk factors for impaired nutrition status in paediatric patients with cerebral palsy. Acta Paediatr.; 101 (6):649-54.
- Martinez-Biarge M., Diez-Sebastian J., Wusthoff C.J., Lawrence S., Aloysius A., Rutherford M.A., and Cowan F.M. (2012): Feeding and communication impairments in infants with central grey matter lesions following perinatal hypoxic-ischaemic injury. Eur J Paediatr Neurol. Article in Press.
- Nicolson S.E., Chabon B., Larsen K.A., Kelly S.E., Potter A.W., Stern T.A. (2011): Primitive reflexes associated with delirium: a prospective trial. Psychosomatics.;52(6):507-12.
- **Oredugba F.A., and Akindayomi Y. (2008)**: Oral health status and treatment needs of children and young adults attending a day centre for individuals with special health care needs, BMC Oral Health.; 8: 30.
- Pellegrino L. (2007): Cerebral palsy. In M Batshaw, N Roizen, L Pellegrino, eds., Children with Disabilities, 6th ed., Baltimore, MD: Paul H. Brookes Publishing, pp. 387–408.
- Rocker G., Young J., Donahue M., Farquhar M., and Simpson C. (2012): Perspectives of patients, family caregivers and physicians about the use of opioids for refractory dyspnea in advanced chronic obstructive pulmonary disease. CMAJ.;184(9):E497-504.
- Shevell M.I., Majnemer A., and Morin I. (2003): Etiologic yield of cerebral palsy: a contemporary case series. Pediatr Neurol.; 28(5):352-9.
- Sohn M., Ahn Y., Lee S. (2011): Assessment of Primitive Reflexes in High-risk Newborns. 1.J Clin Med Res.;3(6):285-90.
- Steven E.H., Peter L.R., Doreen J.B., Robert T.J.P., Stephen D.W., Lisa A., and Dianne J.R. (2009): Stability and decline in gross motor function among children and youth with cerebral palsy aged 2 to 21 year Developmental Medicine & Child Neurology;51(4): 295–302
- Weir K.A., McMahon S., Taylor S., and Chang A.B. (2011): Oropharyngeal aspiration and silent aspiration in children. Chest.;140(3):589-97.
- Whittingham K., Wee D., and Boyd R. (2011): Systematic review of the efficacy of parenting interventions for children with cerebral palsy. Child Care Health Dev.;37(4):475-83.
- Wu H.Y. (2010): Achieving urinary continence in children. Nat Rev Urol. Jul; 7(7):371-7.
- Yeargin-Allsopp M., Van Naarden Braun K., Doernberg N.S., Benedict R.E., Kirby R.S., and Durkin M.S. (2008): Prevalence of cerebral palsy in 8-year-old children in three areas of the United States in 2002: a multisite collaboration. Pediatrics.;121(3):547-54.

8/20/2012