

# Home Care Offered by Family Caregivers to Preschool Children, Suffering From Hemiplegic Cerebral Palsy

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#### **Abstract**

Objectives: The objective of this study was to assess family caregivers' knowledge & practice regarding home care (activities of daily living) offered to preschool children suffering from hemiplegic cerebral palsy (HCP). Methods: A descriptive cross-sectional design was used to collect data from a convenience sample of 50 family caregivers and their preschool children aged from three to less than six years, who are suffering from hemiplegic cerebral palsy. The study participants were recruited from rehabilitation centers, and rheumatic unit in Minia Governorate, Egypt. Family caregiver's were interviewed face-to-face after agreeing to participate in the study. Data was collected by using two tools; a structural questionnaire and observational check list. Results reveled that more than two third (78 %) of family caregivers had an unaccepted level of knowledge regarding hemiplegic cerebral palsy and activities of daily living for their children. The majority (86 %) had unaccepted level of practice toward activities of daily living for their children with hemiplegic cerebral palsy. There was a highly significant correlation between family caregivers' knowledge and practice (r =.567 at p = 0.000). Conclusion: the study reported a clear lack of knowledge about HCP & unaccepted level care from family's caregivers to their children who suffer from HCP. In addition to the practice of family caregiver's were poor in the most aspects of care to their children.

**Keywords:** Family caregiver's knowledge, practice, home care, hemiplegic cerebral palsy.

#### 1. Introduction

Healthy children are vital resources for the future well being of nations because they are the parents, workers, leaders and decision makers of tomorrow. The preschoolers are in the stage of initiative; numerous age appropriate developmental tasks are achieved during this age such as performing or participating in activities of daily living. The preschooler has often mastered the basic skills needed for most self - care activities, including feeding, dressing, washing, and tooth brushing (Pillitteri, 2007). Limitations imposed by disability may restrict motor and social competency, causing the child to become fearful, passive and develop poor self - image (Moustafa, 2002). Cerebral palsy (CP) is one of several disorders that affect control of movement due to developmental brain injury and are grouped together under the term cerebral palsy (Jackson & Vessey, 2004). Falvo (2005) defined CP as a condition which results from damage to the brain before, during or shortly after the birth, it is not a disease, but rather a complex of symptoms covering a wide number of functional impairments, and it characterized by chronic disorders of movement or posture. Hitchcock et al. (2003) stated that the commonly used classification of CP is based on the distribution of the affected limbs (location). That includes; spastic CP which, accounts for 70 %-80 % of all CP cases, and it is further divided by extremities involved into diplegia, hemiplegia and quadriplegia. Hemiplegic cerebral palsy refers to spastic involvement that may affect both extremities on one side of the body (Pillitteri, 2007). Hemiplegic CP occurs in (34%) of CP cases and spasticity affects one half of the body, usually with the arm worse than the leg but sometimes vice versa. Mcintosh; Helms & Smyth (2003) stated that hemiplegic CP derives usually from prenatal circulatory disturbances during pregnancy; the commonest cause is preventricular leukomalacia (PVL) due to hypo perfusion of the brain early in the third trimester, cerebral maldevelopment and major cortical / sub cortical lesions, both in infancy and later childhood. Hemiplegic CP manifested by specific difficulties may not observed during the first 3 to 5 months of the child life, after a perinatal stroke, the child may be neurologically normal until the development of pathologic handedness at approximately 4 to 6 months of age, and he has impaired gross and fine motor coordination, and difficulty moving the hand quickly and frequently unable to grasp small items with pincer grasp, while other children may manifest obvious hemiplegia in the second year of their life (Swaiman et al, 2006). Children with hemiplegic cerebral palsy may have various limitations in activity of daily living that result from movement problems which impair the child ability to live independently. In this case, they will need lifelong assistance in activities of daily living, and they are usually treated at home through family caregivers. Associated problems with cerebral palsy are some times more disabling for the children with CP than the motor disorder, such as feeding, dental, bowel & bladder problems, these problems usually co- exist with CP (Fouad, 2003). Ebnezar (2004) classified the cerebral palsy into three categories (conditions); mild cases of CP are independent in ADLs, and moderate cases of CP need help in ADLs, while



severe CP patient is bedridden and has a wheelchair existence.

The primary goal of CP management is to maximize the potential of CP children and their families to live healthy, active and productive life (Hitchcock et al, 2003). Sloane et al. (2008) reported that best outcomes of CP management will occur when an interdisciplinary team is involved early in management of the child with CP, which should include the primary care physician, psychologist, occupational, physical, speech therapist, educational, and vocational therapist, and social worker. Caregivers play an important role in screening and observing the growth and developmental patterns of children with CP. They encourage, and assist the child to reach the maximum potential and may be needed to reinforce teaching regarding special feeding programs, safety environment, immunizations, vision, hearing and dental screenings and use of adaptive devices. Caregivers who know their family special needs and problems are in the best position to provide guidance and support (Mohamed, 2006). Caregivers of the children with CP are vital members of the professional team; the most important role of them is the lifelong interest in commitment to their children; they may feel helpless and confused, so that they need information, intervention, and a supportive rehabilitation program about their children's condition (Mohamed, 2004). Caregivers need guidance in how the conditions of CP may interfere with or alter ADLs, such as dressing, sleeping and toileting, with appropriate planning and knowledge of strategies to improve the child's functional abilities. Most children with CP can live a fulfilling and productive life (Hockenberry et al, 2005). The responsibility of the home health care nurse is to help the caregivers to manage their time and effort, and teach them how to care for their children, including performing ADLs (Afifi, 2006). The aim of this study was to assess family caregivers' knowledge & practice regarding home care of daily living activities offered to preschool children suffering from hemiplegic cerebral palsy.

#### 2. Methods:

- 2.1 Design: A descriptive correlational cross-sectional design was used to answer the following research questions:
  - (1) What is the knowledge of family caregivers regarding home care of daily living activities offered to preschool children, suffering from hemiplegic cerebral palsy? (2) What is the level practice of family caregivers regarding home care of daily living activities offered to preschool children, suffering from hemiplegic cerebral palsy?
- 2.2 Sample: Convenience samples of 50 family caregivers and their preschool children aged from three to less than six years, who are suffering from hemiplegic cerebral palsy. The study participants were recruited from rehabilitation centers, and rheumatic unit in Minia Governorate, Egypt. Family caregivers were interviewed face-to-face after agreeing to participate in the study.
- 2.3 *Instruments:* Data was collected using two tools: 1) a structured interview questionnaire, 2) observational checklist for home care given by family caregivers.
- I. A structured interview questionnaire was designed by the researchers. It covers the following:
- a. Socio- demographic characteristics: age, gender, level of education, occupation, income, residence, family type, family size, number of children, consanguineous relationship between father and mother, child age, gender, rank, and child age when detecting the disease.
- b. Family health history: maternal and gestational risk factors.
- c. Child medical history: prematurity and associated problems with CP, brain injury, degree of hemiplegic cerebral palsy, use of assistive mobility devices, method of child feeding.
- d. Family caregivers' knowledge: that includes definition, signs, causes, risk factors of hemiplegic cerebral palsy, home care of hemiplegic cerebral palsy children regarding activities of daily living and their expectations regarding their child condition.
- e. Family caregivers' practice of toilet training, child sleeping pattern, hair and nail care, environmental condition and sources of caregivers' information regarding practices.

Responses of the knowledge & practice questions were categorized as correct or incorrect. A score of 1 point was given for each correct response. The total score was calculated by summing the individual score of the 16 knowledge & practice questions, the score range from 1-16, the higher the score, the higher the knowledge & the better the practice.

II. Observational checklist for home care given by family caregivers: was designed by the researchers after an extensive literature review. It covers the following: home care provided to preschool children with hemiplegic cerebral palsy regarding activities of daily living; feeding, feeding precautions, personal hygiene (bathing, dressing and teeth care).

Responses of the practice questions were categorized as correct or incorrect. A score of 1 point was given for each correct response. The total score was calculated by summing the individual score of the 66 practice



questions, the score ranges from 1-66, the higher the score, the better the practice.

A pilot study was carried out on 5 family caregivers and their hemiplegic cerebral palsy children who had the same inclusion criteria as the subjects in this study to assess the validity of the study questionnaires. Modifications were made accordingly & they were not included.

Data Analysis: Data were verified prior to entry. The statistical package for social sciences (SPSS) version 17 was used for data analysis and tabulation. Descriptive statistics such as frequency, mean and standard deviation were utilized in analyzing data presented in this study. A significance level value of  $p = \le .05$  was considered

#### 3. Result

# **Demographic**

Table (1) shows that all family caregivers were females, (82%) of the study sample were married, and (72%) of them had income of less than 100 pound / month. As regard family size (42%) of the sample consists of 3-5 person, while (30%) consisted of more than 8 persons. Only (14%) of the study sample were employees, and (52%) of them were living in urban areas, while (52%) of the study sample were having consanguineous relationship between father and mother of the affected child.



Table 1: Socio-demographic characteristics of family caregivers, and their hemiplegic cerebral palsy children (N=50)

children (N=50)		
Items	Frequency n= 50	percent %
Caregiver's age		
20-29	22	44
30-39	17	34
40-43	11	22
Mean ± SD	$65.0 \pm 37.2$	
Marital status:		
Single	4	8
Married	41	8
Widow	4	82
Divorced	1	8
Educational level		
illiterate / just can read & write	17	34
primary / preparatory	12	24
secondary school	16	32
university	5	10
Child caregivers:		
Mother	43	2
Sisters	4	86
Relatives	3	8
Occupation		
Housewife	43	86
Employee	7	14
Monthly income		
150 -	8	16
250 -	16	32
250 - 600	26	52
Residence		
Urban	76	52
Rural	24	48
Consanguineous relationship	·	
Relatives	26	52
Not relatives	24	48
Family type		10
Extended	77	54
Nuclear	23	46
Family size		10
3-	21	42
3- 6-	21 14	28
9-12	14 15	30
	13	30
Family children number	20	40
1- 3-	20	
	23	46
5-6	7	14
Child gender		
Male	28	56
Female	22	44

Research Question 1: What is the knowledge of family caregivers regarding home care of daily living activities offered to preschool children, suffering from hemiplegic cerebral palsy?

Descriptive statistics were used to answer this research question.

68% of family caregivers don't know the dangerous signs of CP that make it necessary to transfer the child to hospital. In addition (58%) of the study sample viewed that the early detection of hemiplegic cerebral palsy is not important. There is a significant difference between total family caregivers' knowledge scores and total family caregivers' knowledge regarding hemiplegic CP ( $x^2 = 127.8 - P = 0.000$ ), and 54% don't know family



role in early detection.36 % don't know definition of HCP, data of knowledge presented in table 2.

Table 2: Family caregivers' knowledge regarding hemiplegic CP in percentage distribution.

	Respo	<b>X</b> <sup>2</sup>	p			
Knowledge	True		False			
	No.	%	No.	%		
Definition of hemiplegic CP	32	64	18	36		
Signs	33	66	17	34		
Causes	18	36	32	64	127.8	**.000
Importance of early detection	21	42	29	58		
Dangerous signs that needing hospital.	16	32	34	68		
Family role in early detection.	23	46	27	54		

Table (3) show family caregivers knowledge regarding home care of activities of daily living, it was noticed that 64 % of the family caregivers viewed that the position of hemiplegic CP child during feeding is not important, while (86%) of them reported that personal hygiene is important, and 78 % of family caregivers reported that changing child position during sleep is not important. There was a significant differences between total family caregivers' knowledge scores and total family caregivers' knowledge regarding activities of daily living ( $x^2 = 62.841$ - p = .012)

Table (3): Family caregivers' knowledge regarding home care of ADLs.

	Responses (n=50)				X <sup>2</sup>	р
Knowledge	Yes No		No			
	No.	%	No.	%		
- Suitable position during feeding is important for hemiplegic CP child.	18	36	32	64	62.841	*.012
- Making pressure on the jaw during feeding has a benefit for hemiplegic CP child.	25	50	25	50	02.041	*.012
- Personal hygiene is important.	43	86	7	14		
-There is benefit of teeth caring.	17	34	33	66		
- Changing child position regularly during sleeping is important.	11	22	39	78		

Research Question 2: What is the family caregivers practice regarding home care of daily living activities offered to preschool children, suffering from hemiplegic cerebral palsy?

Table (4) shows that (74 %) of the family caregivers don't give enough time for child feeding, while (72 %) of the study sample does not keep the child in semi sitting positions for one hour after meal. In addition to (64) % of them don't inspect the child mouth or remove the remaining food after feeding, There is a significant difference between total caregivers' practice scores and total family caregivers' practice regarding precautions that prevent aspiration during feeding.(p=.008).

Table 4: percentage distribution of Family caregivers' practice regarding precautions that prevent aspiration during feeding of CP child in the present study.

Caregivers' practice	Practice		X <sup>2</sup>	р		
Aspiration precautions :-	Yes	Yes No				
- Observation of the child during feeding and drinking	No.	%	No.	%		
to prevent aspiration.	44	88	6	12		
- Offering suitable food texture for the child.	24	48	26	52		
- Give enough time for swallowing food.	22	44	28	56	289.2	*.008
- Give enough time for feeding.	13	26	37	74		
- Give the child a small piece of food at one time.	29	58	21	42		
- Not pushing food by fluids.	22	44	28	56		
- Inspection of the child mouth after feeding.	18	36	32	64		
- Remove the remains food from the child mouth after feeding.	18	36	32	64		
- Chang the child position if aspiration occurs and making percussion on the child back.	37	74	13	26		
- Keeps the child in Semi setting position (45 degree) for half an hour after meal	14	28	36	72		



Table (5) shows that (82 %) of the family caregivers does not put their children in suitable position during sleeping, and (80 %) of them don't change their children position during sleeping. There was no significant difference between total practice scores and total family caregivers' practice regarding child sleep (p=.905)

Table (5): Family caregivers' practice regarding child sleep.

Caregivers' practice	Prac	Practice			X <sup>2</sup>	p	
	Yes	Yes		Yes No			
Sleeping:-	No	%	No.	%			
-Prepare suitable place or presence of special bed	38	76	12	24			
for the child.							
- Select suitable position for the child when sleep.	9	18	41	82	85.6	.905	
- Change the child position regularly during sleep	10	20	40	80			
for long duration.							
- Help the child to sleep and wake up at stable	4	8	46	92			
time.							
- Decrease or prevent the noise to help the child to	22	44	28	56			
sleep.							

Table (6) revealed that there is a significance correlation between caregivers' total knowledge scores and total practice scores where (r = .567, p = 0.000).

Table (6): Correlation between total knowledge score and total practice score among the study sample (n = 50).

Items	r	P
Total knowledge score	.567	**0.000
Total practice score		

Table (7) shows that there is a significant correlation between educational status of family caregivers with total knowledge scores (r = .521, p = .000) and total practice scores as well (r = .531, p = .000). Mean while there no significant correlation between caregivers age (p = .473) and total knowledge scores or total practice scores(p = .363).

Table (7): Correlation between socio – demographic data and total family caregivers' knowledge and practice.

Caregivers socio- demographic items	Total knowledge		Total pra	actice
	r P		r	P
- Caregiver's age.	.104	.473	.132	.363
- Educational status.	.521	**.000	.531	**.000
- Marital status.	019	.895	113	.433
- Occupation.	.371	**.008	.403	**.004
- Family type.	076	.602	264	.064

# 4. Discussion

This study aimed at assessing family caregivers/ knowledge and practice regarding home care (activities of daily living) offered to preschool children suffering from hemiplegic cerebral palsy. The study used a descriptive design to answer the research question. The study revealed that nearly one third of family caregivers' reported economical problems, not enough rehabilitation services in the hospital they attend for child care such as occupational therapy, difficult transportations were barrier for family caregivers in providing child care.

These results of the study were congruent with Afifi (2003) who mentioned that more than two thirds of caregivers were unsatisfied from follow up services due to many barriers such as insufficient care, expenses and transportation of the child. Price & Gwin, (2008) also reported that the long course of cerebral palsy is a financial burden on the family expenses. The improper community stigma to the child was reported by caregivers as an obstacle facing them in providing care to their CP children, this was consistent with Jackson & Vessey (2004) who stated that a stigma based on the diagnosis of CP is attached to all families and the visibility of this condition may create more stigma in some cultures than in others, and in some cultures the child may be hidden from the outside world. Present study revealed that, the majority of family caregivers have low level of knowledge regarding activities of daily living for their children with hemiplegic CP, which is supported by Afifi (2006) who found that more than half of caregivers had poor knowledge related to activities of daily living



(feeding, bathing, dressing, teeth care, and elimination) and how to provide home care related to these problems and added that knowledge deficit is the main cause of unawareness about the nature of the disease, thus expose the child to risk of complications. The findings of the current study clarified that the majority of the family caregivers had unsatisfactory level of practice in relation to activities of daily living for their children with hemiplegic cerebral palsy. This result was supported by Fouad (2003) who found that the majority of caregivers of CP children had deficit in most aspects of child activities of daily living. The investigator explained that a lack of family caregivers' practice may be due to a lack of their knowledge regarding proper home health care of the child with CP. Home care was considered a basic or complementary part of child rehabilitation program, as mentioned by Mohamed (2004) who suggest that caregivers may be unable to take care of their disabled children at home due to defective knowledge and practice regarding caring of CP child. The current study revealed that there was a highly significant correlation between family caregivers' total knowledge and total practice scores. These results mean that the family caregivers' knowledge had an effect on their practice. When family caregivers have a satisfactory knowledge level regarding their children condition, this will improve their practice regarding daily care of their children with hemiplegic cerebral palsy. This explanation goes in the same line with Ali (2008) who mentioned that when caregivers provided with the basic knowledge about their children condition, developmental prognosis and various treatment approaches, will assist them in practicing new and healthy behaviors and can also change unhealthy behavior.

#### 5. Conclusion

The current study was undertaken to assess family caregivers' knowledge & practice regarding home care (activities of daily living) offered to preschool children, suffering from hemiplegic cerebral palsy. A descriptive correlational cross-sectional design was used to answer the research questions. a convenience sample of 50 family caregivers and their children with hemiplegic cerebral palsy were recruited in this research. The study participants were recruited from rehabilitation centers, rheumatic and rehabilitation unit in Minia Governorate-Egypt. Family caregiver's were interviewed face-to-face after agreeing to participate in the study.

The present study concluded that; a majority of family caregivers had lack of knowledge regarding hemiplegic cerebral palsy, and the majority of them have an unaccepted total level of knowledge scores regarding home care of activities of daily living for their children with hemiplegic CP. There was a considerable lack of family caregivers' practices in most aspects of activities of daily living for their children with hemiplegic cerebral palsy (feeding, personal hygiene, child sleep and toilet training). The current study recommended that training programmes should be conducted for family caregivers to provide them with knowledge and skills regarding caring of their hemiplegic cerebral palsy child, and improving the public awareness toward home care of cerebral palsy child through different types of mass media.

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