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Assessment of Caregiver's Knowledge and Practice Regarding Care of their Children Suffering from Cerebral Palsy

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ABSTRACT

Back ground: Cerebral Palsy (CP) defines a group of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination. Cerebral Palsy is caused by damage to or abnormalities inside the developing brain that disrupt the brain's ability to control movement and maintain posture and balance. Aim: the current study aimed to assess caregivers' knowledge and practice regarding care of their children with cerebral palsy. Research design: a descriptive research design was used. Setting: The study was carried out at Sett Khadra Child Health Center in Helwan refered from Helwan general Hospital affiliated to Ministry of Health and Physiotherapy Unit in Mustafa Hassan Pediatric Hospital affiliated to Fyoum University Hospital. Sample: A purposive sample consisted of 70 children suffering from cerebral palsy and their accompaying caregivers . Tool: consisted of two tools: I: A structured interviewing questionnaire sheet to assess caregivers' knowledge regarding cerebral palsy, II: Observational checklists to assess caregivers' practices regarding care of their children with cerebral palsy. Results: more than three quarter of the studied children were aged from one to less than five year. More than half of the studied children were males. More than two thirds of the studied caregivers had unsatisfactory knowledge regarding cerebral palsy. Less than two thirds of the studied caregivers had inadequate practice regarding care of their children with cerebral palsy. Conclusion: Based upon the results of the current study concluded that, the caregivers had unsatisfactory knowledge and inadequate reported practices about cerebral palsy Also, there were a statistical significant differences between caregivers' characteristics and their total knowledge and their total reported practices regarding care of their children with cerebral palsy. Recommendation: Continuous health education to caregivers regarding cerebral palsy diseases, complications and management plan, monitor study factor affecting of family caregivers' knowledge and practices regarding care of their children with cerebral palsy .Assess need and problem of caregivers'of children with cerebral palsy.

Key words: Caregivers, Knowledge, Practice, Children, Cerebral Palsy.

Introduction:

The term cerebral refers to the brain while palsy refers to the loss or impairment of motor function. Cerebral palsy(CP) affects the motor area of the brain's outer layer called the cerebral cortex, the part of the brain that directs muscle movement. In some cases, the cerebral motor cortex hasn't developed normally during fetal growth. In others, the damage is a result of injury to the brain either before, during, or after birth. In either case, the damage is not repairable and the disabilities that result are permanent lesion in single or multiple locations in immature CNS. (National Institute of Neurological Disorders and Stroke, 2020)

Cerebral palsy is one of the most complex of the common permanent disabling conditions. It is a disorder of movement, muscle tone or posture that is caused by damage that occurs to the immature, most often before birth ,during developing brain. Cerebral palsy is considerd neurological condition caused by brain damage, and it is the most common motor and movement disability of childhood. (Galea et al., 2019)





Helwan International Journal for Nursing Research and Pratctice

Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/

Cerebral Palsy may be accompanied by speech and hearing defects and visual problems, Cerebral mental retardation, seizures, and loss of nerve functions. Children with CP may have problems in movement (crawling, and walking), use of hands (eating, writing, and dressing) and communication. The motor disorders of CP are often accompanied by disturbance of sensation and perception, cognition, communication behavior, epilepsy and other secondary musculoskeletal problems. (Cans et al "2020)

Cerebral palsy is caused by an abnormal development of part of the brain or by damage to parts of the brain that control movement. This damage can occur before, during, or shortly after birth. The majority of children have congenital cerebral palsy CP (that is, they were born with it), although it may not be detected until months or years later. (Bainbridge & Haan, 2022)

Cerebral palsy classified or divided into spastic, dyskinetic and ataxic forms Approximately 70% to 80% of children with CP are spastic. Spasticity is defined as an increase in the physiological resistance of muscle to passive motion. It is part of the upper motor neuron syndrome characterized by hyperreflexia, clonus, extensor plantar responses and primitive reflexes. Spastic Cerebral Palsy is the most common form of CP. Spastic cerebral palsy is anatomically distributed into three types

(Žarković et .,2021& Kruse et al ., 2018).

The nurse has play important role in the nursing care of children with cerebral palsy to cope with disease through providing guidelines as improving nutritional statues, strengthen family support, foster self-care, enhance communication and improve health life. Also, the nurse communicates with the family to learn as much as possible about child's activities at home and enhance self-steam, reduce stress can result from disorder for the child and family ,teach family stress management technique Also, the nurse has play positive role in minimize disability in children with severe cerebral palsy (Ríos, Basantes & Barros., 2023).

Aim of the Study:

The study aimed to assess caregivers' knowledge and practices regarding care of their children with cerebral palsy.

Research Questions:

- 1. What is caregiver's knowledge and practices regarding care of their children with cerebral palsy?
- 2. Is there a relation between characteristics of caregivers and their level of knowledge and practices regarding cerebral palsy?

Subjects and Methods:

- 1) The technical design:
- A) Research design:

A descriptive design was used to conduct this study.

B) Setting:

The study was carried out at Sett Khadra Child Health Center in Helwan refered from Helwan general Hospital affiliated to Ministry of Health and Physiotherapy Unit in Mustafa Hassan Pediatric Hospital affiliated to Fyoum University Hospital.

C) Subject:

A purposive sample was consisted of all available children suffering from cerebral palsy and their accompanying caregivers (70) who attained in the previously mentioned settings under the following inclusion criteria:

- 1-Both gender.
- 2-Children with confirmed diagnosis of cerebral palsy.
- 3- Children free from any other physical or mental disease.





Helwan International Journal for Nursing Research and Pratctice

Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/

D) Tools for data Collection:

Tool (I) Structured interview questionnaire sheet consisted of three parts

Part 1: study subjects' characteristics

- a- Characteristics of the children namely age, gender, weight, height, ranking and education.
- b- Characteristics of the caregivers concerned with age, level of education, job social status and residence.

Part 2: Past and present medical history

- a- Child medical history
- b- Past medical history for caregivers

Part 3: Caregivers' knowledge about cerebral palsy that consisted of the following

- 1- It concerned with caregivers' knowledge regarding cerebral palsy (13 Question) which consisted of 12 multiple choice and one open end question to gather data regarding meaning, causes, types, signs and symptom, learning difficulties, Warning signs, diagnoses, motor skills problem, relationship between brain infections and cerebral palsy, Physical therapy, treatment, protect child from falling, and difficult speaking and language.
- **2-** It concerned with caregivers' knowledge about daily activity delt with caregiver' knowledge regarding daily activity (**8 Question**) which consisted of 6 multiple choice and 2 open end question which consisted of 6 multiple choice and 2 open end question that included Importance of general hygiene, important of position of the child while feeding, Importance of pressure on the jaw during food, important of participation in activities, Importance of exercise, important of changing the child's position regularly during sleep, important of dental care and appropriate time for toilet training.

Scoring system

The caregivers' complete correct answer was scored "two" & those incomplete correct answers was scored "one" and unknown or incoerct answer was scored "zero". Total score was 42 and then converted in to percentage. The total caregivers' knowledge was categorized into unsatisfactory (less than 60%) and satisfactory (60% and more).

Tool (II) Observation checklists

This tool was adapted from Maggioni and Araújo., 2020), Ahmed et al., 2015), Sayed et al., 2010) and World Health Organization WHO., 2009) to assess caregivers' reported practice regarding care of their children with cerebral palsy. It was modified and translated into an Arabic language form by researcher to suit the nature of study. It included nine procedures divided into; Feeding (10 steps), Prevent suffocation (7 steps), Bathing (6 steps), Mouth and teeth care (9 steps), Hand washing (11 steps), Toilet training (7 steps), Sleep (5 steps), coughing and deep breathing exercise (5 steps),

Scoring system

Each practice item done correctly was scored "one" and not done or done incorrectly was scored "zero". The total numbers of steps in the observational checklists were 74 steps. Total score was 74 and then converted in to percentage. The total caregiver' reported practice was categorized into inadequately (less than 60%) and adequately (60% and more).

Validity:

The content validity of the tools reviewed by 3 experts in the field of pediatric nursing to test the content validity. The tools were examined for content clarity, relevance and applicability. Minor modifications of the tools were done according to the experts' comments on clarity of sentences, appropriateness of content and sequence of items.





Helwan International Journal for Nursing Research and Pratctice

Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/

Reliability:

Reliability of the tools tested by using Cronbach's Alpha for testing internal consistency of the tools was performed. The results were 0.845 for structured interview questionnaire, 0.804 for observational checklists.

II. Operational design:

This phase includes a preparatory phase and a pilot study.

Preparatory phase:

Review of the available past, current, national and international related literature and theoretical knowledge of various aspects of the study was done using books, articles, internet, periodicals and magazines to get acquainted with various aspects of the research problem and develop the tools for data collection.

Pilot study:

Pilot study was conducted on 10% of the study subjects which constitute 7 caregivers based on sample criteria. It was conducted to evaluate the clarity and applicability of the study tools. According to the obtained results from the pilot study, some modifications were done in the form of rephrasing and rearrangements of some items. The involved caregivers were excluded later from the main study sample.

Field work:

The actual field work was carried out for data collection over 9 months started from November 2021 till end of July2022 through interviewing every child and their accompanying caregiver's previous mention setting.

Ethical Consideration

Prior study conduction, ethical approval was obtained from the Scientific Research Ethical Committee of the Faculty of Nursing Helwan University. The purpose of the study was simply explained to the caregivers who agree to participate in the study prior to data collection. The researcher was assured regarding maintaining anonymity confidentiality of the subjects' data. Caregivers were informed that they allowed choosing to participate or not in the study and they have the right to withdraw from the study at any time without giving any reasons.

III- Administrative design

After explanation of the study aim an official permission was obtained from the Dean of faculty of nursing and the directors of children's Hospital affiliated to Sett Khadra Child Health Center in Helwan refered from Helwan general hospital affiliated to Ministry of Health and Physiotherapy Unit in Mustafa Hassan Pediatric Hospital affiliated to Fyoum University Hospital to conduct the study.

IV- Statistical design

Data were Organized, entered, and analyzed by using statistical package of social science (IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp). The quantitative data were presented as mean and standard deviation. The qualitative data were presented as number and percentage. The chi-square (χ 2) test was used to find the association between variables of qualitative data.

Results:-

Table (1): showed that 70% and 60% of the studied children were aged from 1< 5 years with mean age 6.28±4.09 and were males respectively. The same table clarified that more than two thirds (35.7%) of the studied children weightly 15< 25 Kg while 41.4 % and 62.8% of them had length/height ranged from 90 to 110 cm and enrolled in special school need respectively.





Helwan International Journal for Nursing Research and Pratctice

Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/

Table (2): clarified that the majority (91.4 %) of the studied caregiver were mother and 81.4% of them were aged from 25 < 35 with mean age 32.46±4.15 years and not working respectively. The same table illustrated that the most (90%, & 92.9%) of the studied caregiver were married and from rural area respectively.

Table (3): showed that more than half (52,7%) of the studied caregiver had complications during pregnancy and 17.1% of the studied caregivers had RH incompatibility and all of them take treatment after delivery.

Fig (1) revealed that more than two thirds (67.1%) of the studied caregivers had unsatisfactory total knowledge regarding cerebral palsy and daily activity.

Fig (2): illustrated that less than two thirds (65.7 %) of the studied caregivers had inadequate reported practices regarding cerebral palsy.

Table (4): Illustrated that statistical significance difference between caregivers' characteristics and their total level of knowledge namely Caregiver, education job and environment when (p-value was <0.00).

Table (5): showed that there were statistical significance difference between caregivers' characteristics and their total reported practices namely education, job and environment when (p-value was <0.00).

Table (1): Distribution of the studied children according to their characteristics (n=70).

Item	NO	%
Age/years		
1< 5	49	70
5 < 10	11	15.7
10 < 15	6	8.6
≥15 years	4	5.7
Mean ±SD	6.28 ±4.09	
Gender	42	60
Male	28	40
Female		
Weight / Kg		
5<15	20	28.6
15< 25	25	35.7
25<35	18	25.7
≥35kg	7	10
Length / height Cm		
70 < 90	24	34.3
90<110	29	41.4
110 < 130	13	18.6
≥130cm	4	5.7
Ranking		
first	30	42.9
second	21	30
third	17	24.3
Fourth	2	2.8





Helwan International Journal for Nursing Research and Pratctice

Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/

Level of education		
nursery	12	17.2
primary	14	20
preparatory stage	0	0
Enrolled in special school need	44	62.8

Table (2): Distribution of the studied caregiver's according to their characteristics (n=70).

Item	NO	%	
Caregiver's			
Mother	64	91.4	
Fathers	3	43	
Grandmother	3	43	
Age /years			
25 < 35	57	81.4	
35 < 45	6	8.6	
45 < 55	4	5.7	
55 <u>≤</u> 60	3	43	
Mean ±SD	32.46 ±4.15		
Level of ducation			
Illiterate	8	11.4	
Primary	12	17.2	
Preparatory	29	41.4	
Secondary	14	20	
University	7	10	
Job			
Not working	57	81.4	
Working	13	18.6	
Social Status			
Married	63	90	
Divorced	4	5.7	
Widow	3	43	
Residence			
Rural	65	92.9	
Urban	5	7.1	

Table (3): Distribution of caregiver's according to their medical history of cerebral palsy (n=70).

Item	NO	%
Complications during pregnancy Complications during delivery	37 33	52.7 47,3
RH Compatibility Incompatibility Unknown	55 12 3	78.6 17.1 4.3
In case of RH incompatibility , to mother take treatment after delivery Yes	12 0	100 0





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Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/ **Figure (1):** Percentage distribution of the studied caregiver's total level of knowledge regarding cerebral palsy and daily activities

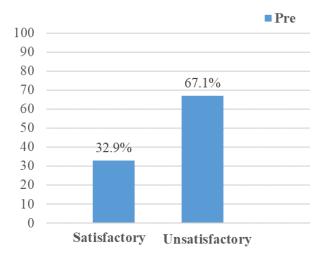
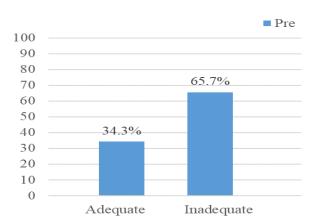


Figure (2): Percentage distribution of the studied caregiver's according to total level of reported practices related to care of their children with cerebral palsy







Helwan International Journal for Nursing Research and Pratctice

Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/

Table (4): Relation between the studied caregivers' characteristics and their total level of knowledge regarding cerebral palsy n=70

	Total level of knowledge					
caregiver's characteristics		Satisfactory	Unsatisfactory			
characteristics	NO	%	NO	%	X^2	P-value
Caregiver						
Mother	21	32.8	43	67.2		
Fathers	2	66.7	1	33.3	3.023	0.221*
Grandmother	0	0.0	3	100.0		
Age						
25 < 35	22	38.6	35	61.4		0.173
35 < 45	1	16.7	5	83.3	4.990	
45<55	0	0.0	4	100.0	4.990	
55 ≤ 60	0	0.0	3	100.0		
Education						
Illiterate	0	0.0	8	100.0		<0.001*
Primary	3	25.0	9	75.0		
Preparatory	5	17.2	24	82.8	25.503	
Secondary	8	57.1	6	42.9		
University	7	100.0	0	0.0		
Job						
Working	13	22.8	44	77.2	14.052	<0.001*
Not work	10	76.9	3	23.1	14.032	<0.001 ·
Social Status						
Married	23	36.5	40	63.5	3.806	0.149
Divorced	0	0.0	4	100.0		
Widow	0	0.0	3	100.0		
Residence						
Rural	19	29.2	46	70.8	5.424	0.020*
Urban	4	80.0	1	20.0	J. 4 24	0.020**





Helwan International Journal for Nursing Research and Pratctice

Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/

Table (5): Relation between the studied caregivers' characteristics and their total level of reported practices related to care of their children with cerebral palsy n=70

	Total reported practices					
caregiver's	Ad	Adequate		adequate	**?	P-value
characteristics	NO	%	NO	%	X^2	
Caregiver						
Mother	22	34.4	42	65.6		0.227
Fathers	2	66.7	1	33.3	2.962	
Grandmother	0	0.0	3	100.0		
Age						
25 < 35	23	40.4	34	59.6		0.144
35 < 45	1	16.7	5	83.3	5.410	
45 < 55	0	0.0	4	100.0	5.410	0.144
55 <u><</u> 60	0	0.0	3	100.0		
Education						
Illiterate	1	12.5	7	87.5		
Primary	3	25.0	9	75.0		<0.001*
Preparatory	5	17.2	24	82.8	22.547	
Secondary	8	57.1	6	42.9		
University	7	100.0	0	0.0		
Job						
Working	13	22.8	44	77.2	17.040	<0.001*
Not working	11	84.6	2	15.4	17.949	
Social Status						
Married	24	38.1	39	61.9	4.058	0.131
Divorced	0	0.0	4	100.0		
Widow	0	0.0	3	100.0		
Residence						
Rural	20	30.8	45	69.2	4.004	0.025*
Urban	4	80.0	1	20.0	4.994	0.025*

Discussion:

As regard characteristics of the studied children the finding of present study showed that more than two thirds of studied children were aged 1< 5 years with mean age 6.28±4.09. These findings were contrasting by **Sogbossi et al (2022)** who carried out a study entitled "Mothers' perception of cerebral palsy in a low-income country of West Africa" and reported that less than two thirds of the studied children aged 1-4years.

Regarding gender of the studied children, the finding of present study showed that less than two thirds of them were male. From the investigator point of view these result might be due to (CP) is typically diagnosed during the first or second year after birth and male children are at higher risk of cerebral palsy, Also this could be due to the greater biological vulnerability of male infants compared to females or might be due to genetic factors as males were at greater risk of prematurity which is the main leading cause of cerebral palsy This finding was supported with that of **Gad et al** (2023) study entitled "effect of an Educational Program about Cerebral Palsy Management on Mothers' Performance" and showed that less than two thirds of the studied children were male.

Considering characteristics of the caregivers, the finding of present study clarified that the majority of studied caregiver were mother and aged 25 < 35 with mean age 32.46 ± 4.15 , These findings were disagreed with those findings





Helwan International Journal for Nursing Research and Pratctice

Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/
of **Horber et al (2020)**, who found in a study about "Severity of cerebral palsy—the impact of associated impairments" and clarified that less than halfe of studied sample were between 25-35 years. Moreover, this result was contrasting with that of **Perveen et al (2023)**, who studied of "knowledge and care among mothers having children with cerebral Palsy" and mentioned that more than three quarters the studied mothers their age between 30-40year.

Concerning the occupation of caregivers, the present study revealed that the majority of studied caregivers not working, From the investigator point of view these result might be due to that the Egyptian mother preferred to stay at home to provide care for their husband and children especially if they had chronic ill child This finding was agreement with those finding of **Nobakht et al (2020)**, who conducted a study about "A web-based daily care training to improve the quality of life of mothers of children with cerebral palsy: A randomized controlled trial" and clarified that the majority of studied caregivers were housewife.

Considering the place of residence of studied caregiver the study finding illustrated that the majority of them from Rural area. From the researcher point of view this might be related to Helwan general hospital all university hospital serve all cases over Egypt especially The finding was congurent to this finding of Hayles et al (2018), who carry out study entitled " Parents' experiences of health care for their children with cerebral palsy" and reported that more than two thirds of mother from rural area. On the other hand this finding was disagreed with the study carried out by Haberfehlner et al (2020), in a study entitled " Instrumented assessment of motor function in dyskinetic cerebral palsy: a systematic review" and found that the most of them from urban area.

In relation to medical history of complications during pregnancy the finding of current study showed that more than half of studied caregiver had complications during pregnancy. This result may be due to mothers' health condition; family medical history and low frequency of antenatal follow up This finding was un similar with **Gad et al (2023)**, who demonstrated that less than half of the studied mothers had complications during pregnancy.

As regard to total knowledge regarding cerebral palsy, the current study result revealed that two third of studied mothers had unsatisfactory total knowledge regarding cerebral palsy. This result may be attributed to the fact that less than half of studied caregiver had Preparatory education. In the same line with **Alruwaished**, **et al.**, (2020) in a study entitled "Knowledge and attitude of caregivers of cerebral palsy children in Riyadh city" who showed that parental knowledge of CP is substantially lacking. Aditionally, **Moenardi et al.**, (2020) in a study entitled "Cerebral Palsy Parents' Knowledge, Attitude, and Behavior at Dr. Hasan Sadikin General Hospital Bandung 2014" who found that more than half of the studied parents had poor knowledge about CP. *Also* In accordance with **Sultana et al.**, (2022) in a study entitled "Early Intervention and Parent Counseling Give Positive Impact in Cerebral Palsy Child" who mentioned that parental knowledge of their child's cerebral palsy is inadequate.

Concerning total reported practice of the studied caregivers regarding to care of their children with cerebral palsy the result of current study clarified that less than two thirds of the studied caregivers had inadequate reported practice. This finding was similar to **Allah et al (2017)**, who studied entitled "Improving the care provided to Hemiplegics Cerebral Palsy Children by Their family caregivers" and found that there was lack of studied mothers practice, And this result was supported by **Hashem & Abd El Aziz (2018)** and reported that more than half of the studied mothers had unsatisfactory reported practices.

Regarding relation between studied caregiver's characteristics and their total knowledge, the current study result illustrated significance statistical difference between caregivers' characteristic and their total knowledge namely Caregiver, education ,job and environment while there were insignificance statistical difference between caregivers' characteristic and their total knowledge namely age and social statues when p-value was <0.00. This result was supported by **Hashem**, & **Abd El Aziz**, (2018) who found that there was statistical significant differences between mothers' educational level and their total level of knowledge about the cerebral palsy and care of associated problems and daily care of their CP children

In relation between studied caregiver's characteristics and their practice the current study result showed that there were statistical significance difference between caregivers' characteristic and their total practice namely Education, Job and environment when p-value was <0.00. This result was contrasted with **Xavier et al.**, (2013) studied to investigate Effectiveness of Selected Feeding Techniques on Knowledge and Practice among Caregivers of Cerebral Palsy Children





Helwan International Journal for Nursing Research and Pratctice

Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/ who found that there was no significant association between the level of knowledge and practice with significant demographic variables such as age, educational status, years of experience and source of information

Conclusion:

Based upon the results of the current study concluded that, the caregivers had unsatisfactory knowledge and inadequate reported practices about cerebral palsy Also, there were a statistical significant differences between caregivers' characteristics and their total knowledge and their total reported practices regarding care of their children with cerebral palsy.

Recommendations:

In the light of the finding of this study, the following recommendations are suggested;

- Continuous health education to caregivers regarding cerebral palsy diseases, complications and management plan.
- Monitor study factor affecting of family caregivers' knowledge and practices regarding care of their children with cerebral palsy
- Assess need and problem of caregivers 'of children with cerebral palsy.

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Helwan International Journal for Nursing Research and Pratctice

Vol. 2, Issue 2, Month: December 2023, Available at: https://hijnrp.journals.ekb.eg/

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